

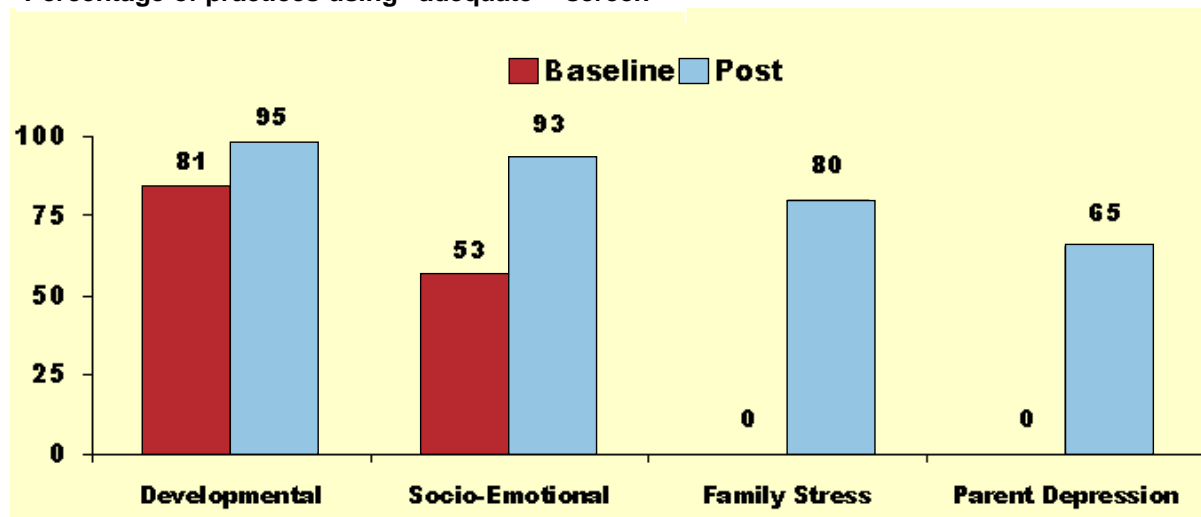
## ABCD II Project Background

Iowa's **1st Five** Healthy Mental Development Initiative builds upon lessons learned from Iowa's Assuring Better Child Health and Development Initiative (ABCD II). ABCD II was a 3-year project funded by the Commonwealth Fund and the National Academy for State Health Policy to improve developmental outcomes and children's readiness to learn. ABCD II focused on Medicaid-enrolled children with the goal of preventing the need for more intensive and expensive care at a later age.

The ABCD II project demonstrated that it is possible to improve patient care through providers' use of the Child Health and Development Record (CHDR), a standardized developmental surveillance tool. The value of private-public partnerships at the community level provides the opportunity to link children and families to services. Iowa's **1st Five** uses these best practices to create a system of care between private and public providers that enhances high quality well-child care.

Iowa's ABCD II sites demonstrated that it is possible to improve patient care.

Percentage of practices using "adequate"\* screen



\* A structured surveillance instrument that includes "red flags" for developmental milestones, social/emotional status, and parenting stress and depression.

Healthy mental development in the first five years



The ABCD II Clinical Panel recommends a three-level system of child health care:

**Level 1 services** – Preventive health care for ALL children

Every regular EPSDT screening for a child birth to five years must include a review of cognitive, motor, language, adaptive, social, and emotional development. Each screening should address parental concerns about the child's growth and development, and review:

- Developmental milestones
- Social, emotional, and behavioral health (including early signs of autism)
- Family risk factors (including parental stress and depression)

The Iowa Child Health and Development Record (CHDR) forms help to identify risk factors and other developmental red flags that signal the need for further assessment and evaluation. Iowa CHDR forms are available at [www.iowaepsdt.org](http://www.iowaepsdt.org) under Screening Resources.

**Level 2 services** – Developmental health care and screening for children AT RISK

Every child birth to five years old that is identified as at-risk in any domain during the initial screening, as well as children the health care provider feels need additional developmental, social, emotional, or behavioral screening, must receive Level 2 screening.

This screening may be completed in the provider's office by the physician, nurse practitioner, or physician assistant, or a paraprofessional so long as the primary health care provider reviews the results. A provider may also refer the child to another community agency for Level 2 screening, or refer the child directly to another professional for Level 3 follow-up assessment and evaluation.

**Level 3 services** – Evaluation, diagnosis, and treatment for children with developmental, social-emotional, or behavioral concerns.

Children who need further evaluation must be referred for systematic, comprehensive assessment specific to the areas of concern. Professionals, as authorized by their scope of practice, will determine the domains to be tested.

*Note: Any child with a speech delay or suspected hearing impairment requires prompt referral for audiological evaluation.*



## Lessons Learned from ABCD II

### **Identification of community-based intervention services:**

Despite multiple gaps and barriers to accessing health care services, care coordinators almost always found some resource to help address the needs of children and families. Care coordinators use their connections from community networking meetings with people from various agencies to identify how a family can be helped. If the answer is not obvious, they persist or seek to change how processes work. Also, if primary care providers want to make referrals on their own, care coordinators can still serve as a resource to help identify local services and fill in the gaps in providers' knowledge base.

### **Power of physician communication:**

Since physicians are viewed as a credible information source, communication between providers and families is very powerful. Referral processes should be formalized between the provider and care coordinator so the family is aware of who can help them remove the barriers they face as they go through the referral process. A provider recommendation can greatly improve the chance that a family will be more receptive when a care coordination contact is made.

### **Significance of building strong provider and community partnerships:**

Strong relationships with the medical community are key to successful referrals. Care coordinators should establish themselves as a professional member of the team who can assist families in getting the care they need. Simple courtesies of the referral process followed within the medical community for years should be observed, such as acknowledging that a referral is received and providing a written follow-up with outcomes, diagnosis (as appropriate), and recommendations for continued care.

### **Standardized surveillance makes a difference:**

Standardized surveillance that includes social/emotional health, family stress, and parental depression makes a difference for improving patient care. Overall, the surveillance form did not make doctors lose time, and in fact, with a few, helped speed up the process. Successful care coordination services demand that the local agency set promotion of healthy mental development as a priority that is reflected in all business decisions of the agency.



**Additional professional training is needed:**

More professional training is needed, especially on how to talk about and respond to family stress and parental depression questions. Although pediatric nurses were initially uncomfortable asking parental depression questions, they later recognized that asking about the well-being of the parent is for the betterment of the child patient. This requires dedicated staff that should be trained in the goals of healthy mental development and referral follow-up.

**Providers need a one-call referral source:**

Time is a valuable component of all well-child visits, and health care providers do not have time to make multiple phone calls every day. When identifying children and families in need of intervention services, medical practices need a one-call referral source to ensure that patients will be linked to the appropriate resources.



## 1st Five Overview

### What is 1st Five?

Iowa's **1st Five** Healthy Mental Development Initiative builds partnerships between physician practices and public service providers to enhance high quality well-child care. In the first years of life, children rapidly develop the social and emotional capacities that prepare them to be self-confident, trusting, empathetic, intellectually inquisitive, competent in using language to communicate, and capable of relating well to others. These emotional skills form the foundation of a child's ability to regulate and express emotions, form close personal relationships with other children and adults, and explore and learn from their environment.

Primary care providers play a key role in supporting optimal healthy mental development in children. In fact, primary health care is the one place nearly all families come into contact with in the child's first five years of life and is ideal for developmental and behavioral screenings.

**1st Five** promotes the use of standardized developmental surveillance and screening tools that support healthy mental development for young children early on. By using a standardized tool for all children, providers are able to identify those at risk for developmental concerns, and link those children and their families with community resources to improve access to appropriate follow up care.

### Why is 1st Five important?

Research tells us that a significant portion of young children are not receiving adequate developmental surveillance and screening. Emotional development in young children is now known to be as important as physical, cognitive, and language development. When developmental concerns are not identified, then it is less likely families will get linked to community-based intervention services. Additionally, many providers are not aware of available resources to refer families to, even when a concern is identified.

Healthy mental development in the first five years



## Social-Emotional Development

**1st Five** helps to identify children at risk of poor social-emotional development by screening for developmental concerns, behavioral concerns, family stress, and caregiver depression. Between 9.5% and 14.2% of children from birth to 5 years of age experience social and emotional development problems that cause suffering to the child and family and interfere with functioning. Only 1 in 6 children with a developmental concern are identified before starting school, leaving teachers to identify and handle most developmental and behavioral problems in the classroom.

## Caregiver Depression

About one in eleven infants will experience their mother's major depression in their first year of life. Children who experience maternal depression early in life may experience lasting effects on their brain architecture and persistent disruptions of their stress response systems. Many mothers may not be identified as having a treatable condition, and only 15 percent obtain professional care. Early intervention for caregiver depression can decrease and even reverse the negative effects on young children.

## Family Stress

Early exposure to adverse experiences, such as poverty, exposure to intimate partner violence, abuse, and family turmoil, predicts the emergence of later physical and mental health problems, including psychological disorders like depression. The more adverse experiences in childhood, the greater the likelihood of developmental delays and other problems. Children with more adverse experiences are more likely to develop physical and mental health problems as adults, including alcoholism, depression, heart disease, and diabetes.

## Intervene as Early as Possible

While there is no "magic age" for intervention, it is clear that, in most cases, intervening as early as possible is significantly more effective than waiting. The brain is much more adaptable in the first five years of life than it is by the time a child starts school. Early treatment of delays or concerns leads to improved outcomes for the family and the child, whereas later intervention is less effective.

Healthy mental development in the first five years



## Better Investments

In addition to improved outcomes for the individual child and family, early interventions lead to considerable savings to society over the long term, with the biggest savings from decreased criminality in adulthood. Several national studies have demonstrated that every dollar invested in early childhood yields \$3-\$17 in return. The RAND group estimated a government savings of \$18,611 per child who underwent early intervention in the Elmira Prenatal/Early Infancy Project, and a savings of \$13,289 per child for individuals receiving intervention in the Perry Preschool Project (figures in 1996 dollars).

However, many children and families do not receive the intervention they need. Programs like **1st Five** are key to helping physicians identify children and families who could benefit from early intervention and connecting them with available services.

The 1<sup>st</sup> Five Model of care coordination also serves as a best practice community utility model. As health care reform starts to utilize medical homes, the 1<sup>st</sup> Five model supports professionals working together for increased patient quality and shared accountability for patient costs.

## How does **1st Five** work?

**1st Five** focuses on children with less intensive needs who are at risk of developmental concerns that may play out later in life if left untreated as a young child. Caregiver depression, family stress, behavioral concerns, or increased risk of developmental delay are some of the issues that may trigger a provider referral to **1st Five**. On average, for every one referral made to a **1st Five** care coordinator from a provider office, an additional 2-3 referrals are identified once the care coordinator begins working with the family.

Healthy mental development in the first five years

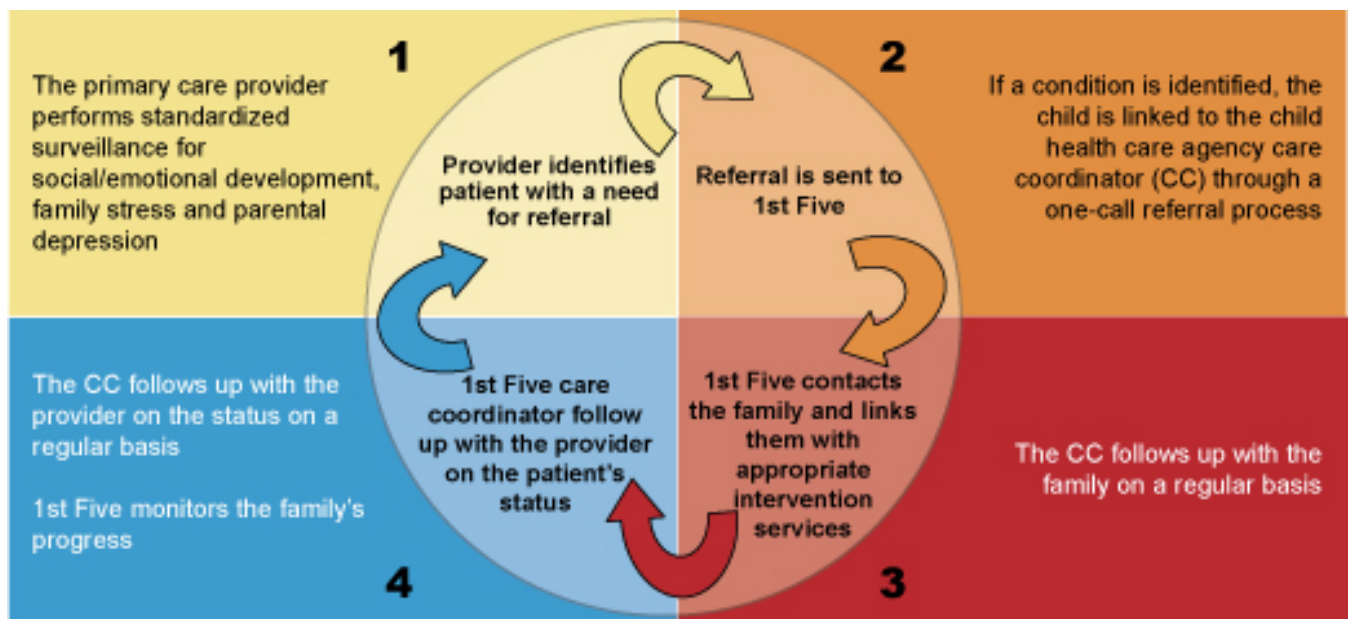


### 1st Five helps to enhance patient care by:

- Promoting primary care provider use of standardized surveillance and screening tools to assess social-emotional development and family risk factors.
- Helping providers integrate developmental screening tools into their practices.
- Linking children and their families to community resources to improve access to appropriate follow-up care.
- Providing feedback to providers on each referral.

The four main objectives of 1<sup>st</sup> Five Healthy Mental Development Initiative are to:

1. Increase the number of primary care providers who are using a standardized developmental screening tool to identify children who are at-risk or need low level interventions.
2. Provide infrastructure building activities such as working with primary care providers and nurse managers on the implementation of developmental surveillance and screening.
3. Educate EPSDT providers and other community providers to increase the knowledge of the importance of developmental screening and social determinants of health.
4. Provide care coordination services to families and provide feedback on referrals to primary care providers.





## 1st Five Success Stories

### Newly Single Father Struggles

A physician in Lee County referred a three-year old whose father was struggling with multiple issues associated with raising a young child as a newly single parent. The child was assessed as speech and toilet training delayed, showing fearfulness and acting out behaviors during the office visit and inappropriate responses to touch. The child's immunizations were also out of date. The **1st Five** coordinator referred the family to services at the AEA, an immunization clinic, lead screening, and the University of Iowa developmental disabilities clinic. The child is now in a high quality childcare setting, which has helped with toilet training progress and support. The father is described as increasingly involved in the welfare of the child and showing follow-through with the support and referrals made available through the **1st Five** initiative.

### Overwhelmed Mom

In Polk County, a nine-month-old child was referred to **1st Five** for health insurance issues. The **1st Five** coordinator contacted the mother and completed a **1st Five** intake form and scheduled a home visit to meet with the mother. While speaking with the mother other issues came up including: depression, family stress, developmental delays and behavioral issues with her older children, her own physical disability, economic and housing difficulties, in addition to employment, educational and child care needs. Based on this relationship and the issues that arose, referrals were made to various resources, including the Child Guidance Center for psychological support for an older child and for mom's depression. Resources were also provided in areas such as employment support, GED classes, childcare, infant care and financial assistance.

### Young Child Exposed to Intimate Partner Violence

Annie, a 4 year-old girl, was referred to **1st Five** because she had been exposed to her father's violent behavior toward her mother and had begun exhibiting aggressive behavior herself. After talking with Annie's mother, the **1st Five** coordinator referred her to the Tri-State Coalition Against Violence. The coordinator also referred the family to a counseling center, which has a young children's group for Annie to attend, and AEA for speech and hearing evaluations for both of the family's children. Annie's mother reported that she is coping better as a result of counseling and that Annie's behavior is improving as well.

### Teen Mom Needs Help with Parenting Skills and Stress Relief

Stephanie, a teen mother of a new baby in Clarke County, was referred to **1st Five** for family stress. The **1st Five** care coordinator connected Stephanie to the local Parents as Teachers group to improve her parenting skills and to mental health counseling to relieve her stress. Stephanie reported less stress now because of being connected to these support services and, as a result, she plans to stay in high school and graduate.

### Sick Kids Need Help with Insurance

In the Dubuque area, a local provider requested **1st Five** assistance for two sick children who presented at their office without insurance. The **1st Five** coordinator located local Empowerment funding to pay for acute office visits for uninsured children and faxed referral voucher forms to the office for payment. Both children were seen the same day. A Medicaid application was approved shortly thereafter, and the children were provided coverage that covered the cost of the previous visits. The availability of Empowerment funding enabled the family to seek care for their sick children from the most appropriate and cost-effective provider. Though Medicaid covered the visits, the referral vouchers were exactly what the family needed to appease the billing office and have their children seen at their medical home. The children continue to be covered by Medicaid and are seeking care at their medical home, and the family was very grateful for the advocacy on their behalf.

### Physician Makes Easy Referral for Developmental Delay

Three-year old Samantha was seen for a well-child exam at one of the participating **1st Five** medical practices that provides comprehensive developmental surveillance. During the assessment process, the physician identified significant speech and developmental delays. The medical staff referred Samantha to the local **1st Five** care coordinator, who was able to link the family to the local AEA and the University of Iowa for further testing. The **1st Five** care coordinator linked the child and family to services and provided follow-up referral status to the medical practice. The referring physician expressed gratitude and relief to the care coordinator for the one-call easy referral process. Medical practices are more apt to provide comprehensive developmental assessments when effective referral processes are in place.

### After Screening Mom Becomes Convinced that Twins Need Early Intervention Services

A local physician referred premature infant twins for possible developmental delays. The mother had previously turned down intervention services, but became more receptive following administration of the Ages and Stages Questionnaire (ASQ), which indicated physical delays. The **1st Five** care coordinator was able to connect the family with the local AEA. AEA provided initial testing, and OT and PT twice per week for the twins. The **1st Five** care coordinator continued to provide follow-up and reassurance to the mother. The twins have made developmental progress and the mother stated she is happy with the services and relieved to have help for her twins. The referring physician was updated by fax on the progress of his referral.

### Referred for Developmental Delay, Family Stress Identified As Well

Carrie, aged nine months, was referred because of a gross-motor developmental delay. After speaking with the family, the **1st Five** care coordinator also discovered family stress related to financial difficulties. The coordinator referred Carrie to Parents as Teachers, Early ACCESS for evaluation for occupational therapy, and the UIHC Pediatric Ophthalmology Clinic. The **1st Five** coordinator also referred Carrie's mother to the Maternal Health program for resources for her current pregnancy. The family was also referred to a social worker, heating assistance, food assistance, a local food pantry, and transportation assistance to Iowa City. Carrie's gross motor development has improved and the family's financial stress has decreased as a result of **1st Five**'s referrals. For this single medical referral, an additional nine referrals were identified to benefit this child and family.

### Speech Delay Triggers Referral, Resource Needs Identified As Well

A child was referred to **1st Five** by a children's clinic physician for speech concerns. The **1st Five** coordinator completed a home visit, where the mother reported intense financial and resource needs as well. **1st Five** was able to address both concerns, whereas a medical provider may not know where to refer a family for resource needs. **1st Five** was able to refer the family to an organization that could provide diapers and baby wipes, as well as holiday assistance resources. The child was also referred to Early ACCESS and has received ongoing speech therapy.



## Lack of Resources for Behavioral Concerns Causes Intense Family Stress

A four year-old male child was referred to **1st Five** by an ARNP in a local medical practice for behavior and developmental concerns. As the boy had been kicked out of several child care centers, his mother had quit her job to care for him full-time. This was causing severe stress, anxiety and financial strain on the family as a whole. Mom stated that she felt alone and frustrated. Mom had taken the child to several doctors without receiving a diagnosis or any treatment. The local **1st Five** coordinator referred this child to the Child Health Specialty Clinic (CHSC) in Creston. The coordinator explained to mom that it will be helpful for the child to be seen and evaluated by the CHSC in order to obtain a diagnosis for his behaviors and delays and for ideas on how to treat this child. Mom sounded very relieved that her son may finally receive the attention that he needs and that their family could soon be under less stress and anxiety. The **1st Five** coordinator also referred mom to counseling, a support group, and DHS for any support programs that the family may be eligible for, and depending upon the diagnosis of the child, the child and family may qualify for more programs and financial assistance. Prior to **1st Five** being implemented, the primary care providers did not know where to refer the patient and what resources were available to the patient or family. Now, however, the family is looking forward to a reduction in stress and anxiety as a result of **1st Five**'s referrals.

## Where to Go for Help When a Child's Disability is Overwhelming

A family in Polk County was referred to **1st Five** for parental stress and possible depression. The **1st Five** care coordinator made a home visit to the mother to discuss the family's needs. The mother admitted feeling overwhelming stress and depression related to caring for a severely disabled child. The **1st Five** coordinator referred the mother to a family support program in her area that will provide in-home counseling and parent education and case management services. Additionally, the **1st Five** coordinator accompanied the mother on a visit to Child Serve to discuss available options for respite care. The family was also able to apply for and receive food assistance, Medicaid, and holiday assistance. The **1st Five** coordinator was able to provide ongoing emotional support and communication assistance to this mother to encourage her to follow through with referrals, something that is more difficult for busy medical practices to do.



## Grandparent Needs Help with Parenting

A medical practice referred two young children to **1st Five** for possible developmental delay, as well as behavioral concerns. The Marion County Public Health **1st Five** care coordinator contacted the family, discovering that the children were being cared for by older relatives during the long-term incarceration of both of their parents. The family was under a great deal of stress and was unsure where to turn to for help. In addition to referring both children to the Area Education Agency for developmental and behavioral concerns, the family needed help finding parenting and mental health counseling resources. The **1st Five** coordinator referred the family to Children and Families of Iowa for counseling, home visiting programs, Southern Iowa Resources for Families, and The Family Place for resources. While the process has been slow for this family, the children's guardian is beginning to trust the **1st Five** coordinator and her referral suggestions.

## Foster Parent Overwhelmed and In Need of a Pediatrician

Ann, a foster mom of a five-year old boy with behavioral issues and special medical needs, was referred to **1st Five** for stress. The **1st Five** care coordinator linked the family to the appropriate medical services, locating those that would accept Medicaid. The care coordinator also located community-based services such as the local Community Circle of Care, which provides support groups and family activities. Ann later told the **1st Five** care coordinator, "Thanks for caring so much, I now know who to call to get the help I need."

## Mom in Crisis Remembers 1st Five Parent Questionnaire Coming at the Next Well-Child Visit

After 10 years of marriage, Carla's husband unexpectedly walked out on her and their 3 children. One calming thought for Carla occurred when she remembered her two-year old's well-child exam was scheduled for the next day. Prior appointments with her child's doctor included questions about her child's social-emotional development and family stress and depression. This would allow her to get connected to services that she had no clue how to access. Following a referral to **1st Five** by her child's doctor, the **1st Five** coordinator connected Carla to WIC, food assistance, housing information and financial assistance.



## Depressed Mom Needs to Talk to Someone

Shelly, a mom new to the community, was referred to **1st Five** by her child's pediatrician for possible caregiver depression. When the **1st Five** coordinator contacted her, Shelly began to cry over the telephone, saying she felt overwhelmed and had no one to talk to. Shelly was concerned about what others might think if she sought counseling and was unsure if her insurance would cover counseling. The **1st Five** coordinator provided information to Shelly on the possible impact that depression might be having on her young child and what she can do to minimize any negative effects. The **1st Five** coordinator referred Shelly to her Employee Assistance Program for initial counseling and helped her learn about her insurance coverage for further mental health counseling. Shelly was also referred to the local Empowerment/Prevent Child Abuse Iowa –funded respite program to give her a parenting break when needed and to Parents as Teachers for in-home parenting support. After starting counseling, Shelly told the **1st Five** coordinator, "The information that you provided was very useful. Thank you very much for your time and help. You helped me to see that it was important to take care of myself in order for me to take care of my child."

## Mom Afraid of Losing Custody Accepts Help from 1st Five

An infant in Dallas County was referred to **1st Five** for family stress. The infant's mother was wary of "the system" as she perceived it, but because the referral came from her child's pediatrician, with whom she had a trusting relationship, she was willing to follow through with **1st Five**. The **1st Five** care coordinator was able to refer the family to various financial resources as well as counseling through the Family Safety, Risk and Permanency team at Visiting Nurse Services of Iowa. The care coordinator also worked with the mother to help alleviate her fears of the Juvenile Court system and worked with the Department of Human Services to coordinate other services for this family.

## Child Referred for Possible Autism Diagnosis in Need of Many Services

Millie, a four-year old, was referred to **1st Five** by her physician for further screening for autism. The Taylor County **1st Five** coordinator linked her to Child Health Specialty Clinics for further evaluation and Growing Strong Families for home support, as well as Medicaid, food assistance, and Bridge to Care transportation assistance to medical appointments. With the help of AEA and these other comprehensive interventions, Millie was able to attend preschool that fall. Millie's mother still accesses **1st Five** care coordination services as needs arise and she is not sure of available community resources.





### Grandmother Surprised to Know That These Services Exist

Pat, a 2 ½ year old in Story County, was referred to **1st Five** by her pediatrician for speech delay. The **1st Five** care coordinator linked Pat to Early ACCESS and the Early Head Start home visiting program. Pat's grandmother and guardian was relieved to discover that programs like **1st Five** and Early ACCESS existed and told the **1st Five** coordinator, "You just made my day."

### Pediatrician Unaware of All the Services Available for Autistic Child

An autistic child already receiving Early ACCESS services was referred to **1st Five** in Marshall County, as the referring pediatrician was unsure what other services may be beneficial for the child. The **1st Five** coordinator contacted the family to discuss their needs. The child's mother was concerned that AEA was not offering speech therapy services over the summer. **1st Five** was able to refer the family to an alternative speech language pathologist to use over the summer months for continuity of care. Additionally, the care coordinator provided resources on autism and autism specialists close to home.

### 1st Five Finds Services and Information for Child with Speech Delay

Sam, a three-year old, was referred to **1st Five** by his pediatrician for a speech delay and lack of toilet training. **1st Five** provided child development information to the family on toilet training and referred the child to the local AEA for speech evaluation. AEA intervened and the child's speech improved. Sam's parents shared how much their stress and worries about Sam had been reduced now that they're communicating with Sam like any normal three-year old.

### Some Families Are Harder to Serve than Others

An infant was referred by her physician due to concerns with the child's hearing. In addition, the child was behind in her immunizations. Phone calls were not returned, but the **1st Five** care coordinator was able to link the family with Early ACCESS. The Early ACCESS coordinator was able to make a home visit, determining that an older sibling was also in need of services. The mother seemed to be suffering from depression as well. Unfortunately, before referral services could be completed the family moved out of the state.

## **1st Five** Overview of Online Resources

### **1st Five Healthy Mental Development Initiative**

[www.idph.iowa.gov/1stFive](http://www.idph.iowa.gov/1stFive)

The 1st Five website offers information for parents, health care and other service providers, and site coordinators, as well as other community stakeholders. The website provides an overview of the 1<sup>st</sup> Five initiative and links to further information on healthy mental development in young children. 1<sup>st</sup> Five materials and up-to-date information on the progress of the project will also be available.

### **Smart Beginnings**

[www.smartbeginnings.org](http://www.smartbeginnings.org)

Virginia's Plan for Smart Beginnings brings public and private agencies and organizations together. As partners, these groups work with the purpose of building and sustaining a system in Virginia to support parents and families as they prepare their children to arrive in kindergarten healthy and ready to succeed. The site contains resources for parents and caregivers, and also contains information about the program. Smart Beginnings is sponsored by the Virginia Early Childhood Foundation.

### **Early Childhood Iowa**

[www.earlychildhoodiowa.org](http://www.earlychildhoodiowa.org)

The Early Childhood Iowa Web site serves as a site to promote Iowa's system of systems in the area of early care, health, and education. Early Childhood Iowa is a confederation or alliance of stakeholders in early care, health and education systems that affect children age 0 to 5 in the state of Iowa. Its purpose is to support the development and integration of an early care, health and education system for Iowa.

### **Zero to Three**

[www.zerotothree.org](http://www.zerotothree.org)

The mission of Zero to Three is to support the healthy development and well-being of infants, toddlers and their families by informing, educating and supporting adults who influence the lives of infants and toddlers. The site contains information for parents, professionals and public policy. There are numerous resources available to order, and other useful information available free of charge.

Healthy mental development in the first five years





### **Mental Health: A Report of the Surgeon General**

<http://www.surgeongeneral.gov/library/mentalhealth/chapter4/sec3.html>

This site gives an overview of mood disorders, and also provides links for additional information concerning mental health, anxiety, schizophrenia, service delivery, and other services and supports.

### **National Association for the Education of Young Children**

<http://www.naeyc.org/>

The site contains short articles posted each month. The articles are designed for parents and other adults involved with children on a daily basis. Early childhood programs involved in the NAEYC accreditation process frequently use these articles in newsletters to help families and others learn more about giving children a great start.

### **Ounce of Prevention**

[www.ounceofprevention.org](http://www.ounceofprevention.org)

The Ounce of Prevention Fund is dedicated to ensuring that, beginning at birth, children in low-income families can overcome the challenges of poverty and enter kindergarten fully prepared to achieve. The site contains publications and other information about the program and program enrollment.

### **Early ACCESS Iowa**

[www.earlyaccessiowa.org](http://www.earlyaccessiowa.org)

Early ACCESS is a partnership between families with young children, birth to age three, and providers from the Departments of Education, Public Health, Human Services, and the Child Health Specialty Clinics. The purpose of this program is for families and staff to work together in identifying, coordinating and providing needed services and resources that will help the family assist their infant or toddler to grow and develop.

### **Beyond the Blues**

[www.beyondtheblues.info/default.htm](http://www.beyondtheblues.info/default.htm)

The site provides information on perinatal depression, additional resources to aid persons suffering from perinatal depression, and help options. The site also includes information on how a person can be linked with services.



### **American Academy of Pediatrics**

[www.aap.org](http://www.aap.org)

The AAP is dedicated to the attainment of optimal physical, mental, and social health and well-being of infants, children, adolescents, and young adults. The Web site contains a number of information resources regarding parenting, health topics, professional education, advocacy, and much more. The site also contains a number of publications that may be purchased using the online bookstore.

### **Enhancing Developmentally-Oriented Primary Care**

[www.edopc.net](http://www.edopc.net)

EDOPC is a successful Illinois initiative to promote developmental screening within private practices across the state. The EDOPC website offers useful resources for providers and others who wish to implement early screening.

### **Center on the Developing Child at Harvard University**

<http://developingchild.harvard.edu/>

This website offers science-based data on child development and public policy recommendations for improving care to young children. The Center on the Developing Child at Harvard focuses on health disparities and the long-term effects of poverty and family stress on young children.

### **Family Violence Prevention Fund**

<http://www.endabuse.org/>

The Family Violence Prevention Fund provides programs, information, and public policy recommendations for preventing family violence towards women and children. The website includes information on implementing public health programs to reduce family violence and to mitigate the effects of violence on young children.

### **EPSDT Care for Kids**

[www.iowaepsdt.org](http://www.iowaepsdt.org)

The EPSDT Care for Kids site offers information on screening tools and recommendations, as well as billing procedures, for providers and those working directly with providers.

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### **First Signs**

<http://www.firstsigns.org>

This website provides information on early detection and intervention for developmental delays, including autism. The site also includes resources for parents concerned about their child's development.

### **Bright Futures**

<http://www.brightfutures.org>

Bright Futures is a joint initiative of the HRSA Maternal and Child Health Bureau and the American Academy of Pediatrics dedicated to building trusting relationships between providers, children, families, and other health professionals. This website contains links to a number of resources and guides for implementing surveillance and screening, as well as current AAP recommendations for medical providers.

### **Iowa Adverse Childhood Experiences Study**

<http://www.iowaaces360.org>

The first years of a child's life can have a profound impact on future learning, behavior and overall well-being. The Central Iowa ACEs 360 Steering Committee is leading efforts to raise awareness of the life-long impacts of childhood trauma and to support initiatives working to prevent or mitigate its effects. A presentation on The ACE Study in 2011 inspired several Central Iowa organizations to take action to address its findings. The Central Iowa ACEs 360 Steering Committee brought these engaged members together to collaborate on efforts to measure ACEs data in Iowa, raise awareness of the study and identify effective interventions to minimize the risk of ACEs.

Healthy mental development in the first five years



## 1st Five Initial Contact Meeting with a Practice

Building rapport is essential for maintaining strong relationships among the **1st Five** care coordinator, physician practices, and families in need of services. These relationships foster trust and commitment, and are critical to the success of the goals of **1st Five**.

### Three questions to address at the initial meeting:

- What's in it for them?
- What are we asking them to do?
- How can we help them do it?

It is necessary to take an interest in learning what is important to each provider. How do they handle their information? Do they like a lot of details, or do they prefer the big picture? Then, tailor your meeting to accommodate their preferences. The way communication is received and responded to is heavily impacted by the way you look, how you sound, and what you say. Shape your body language, gestures, voice tone, and speed to that of your audience.

Make sure you are on time, organized, calm and collected. It is important to understand that you are the message. How you say things and how you show an appreciation for their time and energy will influence the way your message is received. Professional attire can also increase the credibility of your message.

### Before your meeting:

- Plan for having either the **1st Five** medical consultant or state coordinator to attend, if at all possible.
- Arrange meeting dates, times and locations. Who will be invited to the meeting? (Physicians, nurses, office personnel, supervisors, etc.) How many people will be attending?
- If you are holding your meeting over the noon hour, provide lunch for the meeting participants. This shows them that you understand that their time is valuable, and you appreciate them taking the opportunity to meet with you.
- Identify local family referral resources in that community. This will show the provider office that you are serious about the program, and that you are aware of local resources to improve patient care.
- Create an agenda for the meeting. This will help you stay on track while covering all necessary information.



- Make copies of handouts and any other material that may enhance understanding (e.g., CHDR forms, referral algorithm, etc.). Using different colors for each handout will make identification easier. If you are planning to use a PowerPoint during your presentation, always have a contingency plan in case technical difficulties arise.
- Don't forget: name tags, sign in sheet, and reminders a few days before the meeting. If necessary, include directions to the location for staff and/or presenters. Include the address and zip code of the location for those using online direction tools.

### During your meeting:

- Welcome all attendees to the meeting and introduce yourself. Have attendees introduce themselves as well.
- Distribute any meeting materials and the meeting agenda. Don't assume that everyone is aware of the meeting's purpose. If a written meeting agenda is not available, briefly discuss the purpose at the beginning of the meeting.
- If you have been working with a physician champion/office champion, refer to their involvement so far. This will show an appreciation for their time and effort.
- Keep the meeting on track, and end the meeting on time. Build in some extra time for questions. No one minds finishing early, but finishing late is most objectionable.

### After your meeting:

- Follow up with the physician/office champion on any questions they may have. If a physician/office champion has not yet been identified, schedule a meeting with potential candidates to address any questions or concerns they may have regarding **1st Five**. Invite the physician and/or office champion to join your community coalition.
- Schedule a training meeting to familiarize all medical/office staff with **1st Five**'s referral process.



## Addressing the main issues:

### What's in it for them?

**1st Five** understands that a physician's time is valuable, and the referral process can be lengthy. That is why **1st Five** is here, to help save the physician time while enhancing high quality well-child care.

### What are we asking them to do?

The goal of **1st Five** is to build partnerships between primary care provider practices and public service providers to enhance high quality well-child care. To accomplish this goal, **1st Five** is asking that providers include social/emotional surveillance and screening into every well-child visit. This can be done through using the recommended CHDR forms, or some combination of the recommended social/emotional questions; including screening for parental depression, family stress, and autism.

If a concern is identified, physicians are to refer those identified to their local **1st Five** care coordinator for services. The care coordinator will then provide follow up and link individuals with the proper intervention services. The care coordinator will also investigate any additional services the family may need.

It is important to mention that **1st Five** is not meant to duplicate or replace an already existing relationship between the provider and a referral agency. **1st Five** can support this existing referral by "filling in the gaps." For example, if the practice refers to Early ACCESS, **1st Five** can assist in improving the process for follow-up if a problem occurs. **1st Five** can assist with finding referral sources for families when it is not an obvious EA referral, but rather for a child who may have some concerns, and who continues to "fly under the radar." Remind the provider that **1st Five** focuses on children with less intense needs who are at risk of developmental concerns, but whose families are often told to "watch and wait". Referrals for these children are typically overlooked by providers.

### How can 1st Five help?

The purpose of **1st Five** is to help eliminate any barriers that may interfere with patient care. Whether the problem is lack of time, lack of referral sources, or the unwillingness of a caregiver to follow through with a provider referral, **1st Five** can help. After the physician makes the referral, **1st Five** coordinates all services and follows up with the primary physician regularly on the patient's progress. If community resources are not obvious or additional services are needed, the **1st Five** care coordinator will explore every avenue to ensure that each family receives the appropriate intervention services and follow up care.

## Healthy mental development in the first five years



**Clinic:** XXXXX  
**Provider:** XXXXX, DO  
**Date:** July XX, 2013

**Client:** XXX YYYYY  
**DOB:** 05.XX.2010

### Referral Summary

#### Final

- **Referral**

- Referral made to 1<sup>st</sup> Five on XX.XX.XXXX for language delay.

- **Contacts**

- Multiple contacts with **XXXX YYYYY**, mother, by phone and letter.
- Reviewed 1<sup>st</sup> Five – Healthy Mental Development Initiative and care coordination and referral services with mother.

- **Concerns**

- Discussed referral, surveillance tool, and mother's concerns. Ms. **XXXXX** stated **Child** has a limited vocabulary and speech. He has a history of head trauma at birth.
- Family has single, self-employed income and financial stress.
- Identified referral needs for Early ACCESS assessment of language development for **Child** and information about financial resources, health insurance, and options for family.

- **Referrals/Information**

- Received mother's verbal permission to make a referral to Early ACCESS. Completed referral to Early ACCESS at Heartland AEA. Early ACCESS will follow-up with family to discuss evaluation.
- Mailed resource Early ACCESS brochure and information about free/subsidized health care for parents, free/subsidized preschools, food, low-income energy assistance, and clothing.

- **Follow-up**

- Completed first follow-up call on XX.XX.XXXX. Ms. **YYYYY** states Early ACCESS called and an appointment for **Child** is scheduled for next week.
- 1st Five will follow-up after the Early ACCESS appointment to determine if additional coordination or referrals are needed.
- 1<sup>st</sup> Five completed a follow-up call after the Early ACCESS appointment.
- Ms. **YYYYY** reports that an Early ACCESS Service Coordinator and Speech Therapist visited the **YYYYY** home the week of July 14 and completed a developmental assessment of **Child**. She states Early ACCESS reported **Child's** development as normal at this time. She is satisfied with the information provided from the assessment. The Early ACCESS staff encouraged Ms. **YYYYY** to request another assessment in six months if she continues to have concerns about **Child's** development. They also provided information about hearing screens and suggested **Child** also receive a hearing screen. Ms. **YYYYY** states she will schedule a hearing screen, when she is more mobile in recovering from her broken ankle.
- Ms. **YYYYY** reports that the financial assistance information sent by 1<sup>st</sup> Five is helpful to her and her husband.

- **Future**

- Early ACCESS staff encouraged Ms. **YYYYY** to request another assessment in six months if she continues to have concerns about **Child's** development.
- Early ACCESS staff provided information about hearing screens and suggested **Child** also receive a hearing screen. Ms. **YYYYY** states she



will schedule a hearing screen, when she is more mobile in recovering from her broken ankle.

- No other 1<sup>st</sup> Five services are requested at this time. A closing letter was sent with a business card for future needs or concerns.
- If concerns exist at future appointments, please refer to 1<sup>st</sup> Five again. We will work with the YYYYY family to identify additional information and resources.

Thank you,

XXX ZZZZZ

1<sup>st</sup> Five Team Lead

**Engaging Medical Providers to Implement Developmental Screening:  
Barriers and Opportunity  
Steven L. Wolfe, MD**

**Understand the principles and have an approach to engaging primary care practices in pediatric developmental screening.**

**Memorize Your Message with KISSS**

- Keep it simple
- Keep it short – attention span 10-15 minutes
- Keep it scientific

Remember, TIME IS LIMITED!

**Pre Visit Homework:** Become familiar with practice culture, attitude toward, and history of change processes and attitude toward developmental screening. Identify a leader – physician/nursing/administrative. Identify a champion implementer. Identify perceived barriers.

**Curve of Change:** It is important to find the innovators and forget the laggards.

**Remember, it's about the relationship:** Think, what is my “hook” into the practice? Complete a pre-visit, a visit and revisit. Make a personal follow-up.

**Know Your Products – Talk Team and Medical Home:** Identify your goal and role, i.e. how can you help? Help practice and physicians be professionally successful. Help practice identify role of others in the process.

**PDSA Cycles:** Break process into small pieces, for example: pick a task you can do by Tuesday, conduct a training, offer to train staff on MCHAT/ASQ.

**Ask – Tell – ASK:** If people commit orally or in writing to an idea or goal, they are more likely to honor that commitment. Ask for an action plan (remember, small steps).

**Review physician practice operations and the barriers to process improvement activities.**

**Barriers:** What does the practice see as barriers to implementation of screening? What are the options for overcoming the barriers? Examples of barriers: technology; personnel: number, skills, attitude, knowledge; space; costs/reimbursement; efficiency and workflow; systems/compliance.

**Understand the clinical billing process for developmental screening.**



AGENCY LOGO

TO: [MEDICAL PRACTICE NAME]

FROM: [AGENCY NAME]

DATE:

SUBJECT: 1<sup>st</sup> Five Healthy Mental Development Initiative

This *Letter of Commitment* shall define the terms of collaboration for the period of October 1, 2013 to September 30, 2014 for the purpose of maintaining partnerships between medical practices and public service providers to enhance high quality well-child care for the birth-five patients and families [Medical Practice Name] serves.

[MEDICAL PRACTICE NAME]'s roles and responsibilities toward achieving project goals and objectives:

- Assess children ages birth to five for social/emotional development, family stress, and caregiver depression at a minimum, during well-child visits using standardized surveillance and/or screening tools.
- If concerns are identified, refer family to 1<sup>st</sup> Five coordinator via [insert previously agreed upon method of referral].
- Provide regular feedback to the 1<sup>st</sup> Five coordinator regarding ways to improve the referral and follow-up process.
- Administer a standardized surveillance and/or screening tool at recommended AAP intervals (outlined in the latest edition of Bright Futures).
- Will work with 1<sup>st</sup> Five site coordinator to identify practice training needs on issues that impact children's social-emotional development.
- Will work with 1<sup>st</sup> Five site coordinator to provide input on evaluation needs.

[AGENCY NAME] roles and responsibilities toward achieving program goals and objectives:

- Maintain a streamlined process and care coordination for patient referrals for all family needs related to the child's social/emotional development.
- Contact referred families and link them with appropriate intervention services.
- Provide notification of the referral results to participating medical practices.
- Maintain contact with medical practice related to the effectiveness and efficiency of identification, referral, and follow-up processes.
- Identify and maintain an ongoing directory of community referral resources.

This agreement does not involve the exchange of funds between the parties. This agreement may be terminated by either party by providing written notice to the other party at least ten days in advance of the date of termination. This *Letter of Commitment* is entered into by [AGENCY NAME] and [MEDICAL PRACTICE NAME] on dates and signatures shown below.

[MEDICAL PRACTICE NAME/TITLE]

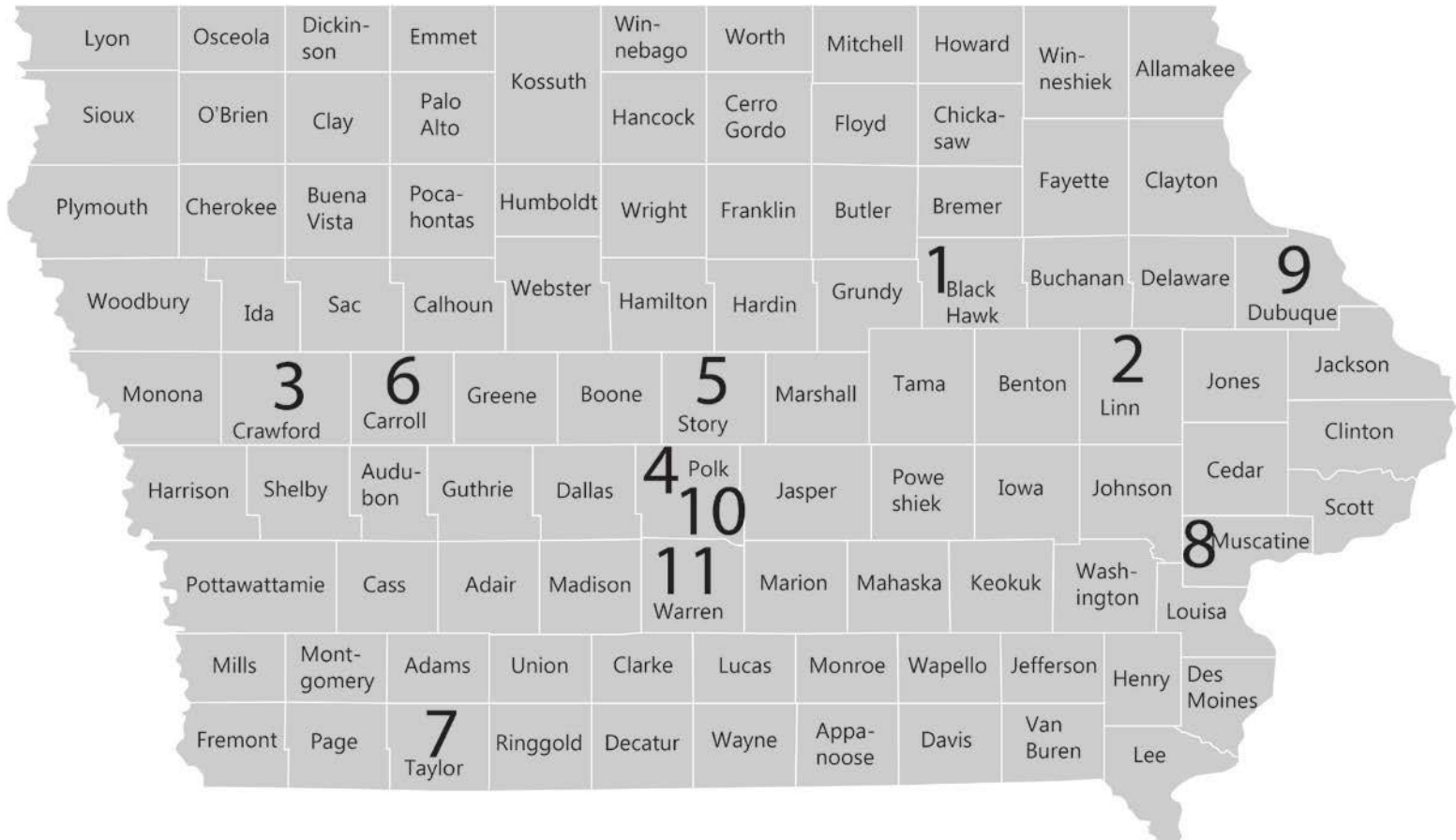
Date

[AGENCY NAME/TITLE]

Date

**Comment [SD1]:** This date can be changed/removed. The purpose is to renew the commitment each year, but with adequate communication between site and provider, this may not be a necessary component of the letter.

# ASQ Trainers



1. **Black Hawk County Health Department**  
1407 Independence Ave. Room 446  
Waterloo, IA 50703  
Marsha Platt [mplatt@co.black-hawk-ia.us](mailto:mplatt@co.black-hawk-ia.us)
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4. **Iowa Department of Public Health**  
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8. **Trinity Muscatine Public Health**  
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Jamie Walker [Jamie.walker2@unitypoint.org](mailto:Jamie.walker2@unitypoint.org)
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Cynthia Klein [cynthia.klein@unitypoint.org](mailto:cynthia.klein@unitypoint.org)
10. **Visiting Nurse Services of Iowa (VNS)**  
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Molly Main [MollyM@vnsia.org](mailto:MollyM@vnsia.org)
11. **Warren County Health Services**  
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Indianola, IA 50125  
Kate Honer [kateh@co.warren-ia.us](mailto:kateh@co.warren-ia.us)

# Why the ASQ and ASQ: SE ?

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## ASQ Ages and Stages Questionnaire

### ASQ:SE Ages and Stages Questionnaire Social Emotional

The ASQ and the ASQ:SE have been identified by Department of Public Health, Department of Human Services, Department of Education, and Child Health Specialty Clinics as the screening tool that State resources will be directed towards.

The ASQ and the ASQ: SE have been endorsed by both Early ACCESS and 1st Five.

The ASQ and ASQ: SE should replace outdated tools such as the Denver.

#### ASQ

The ASQ's sensitivity ranges from 70 to 90 percent and its specificity ranges from 76 to 91 percent. The tool was standardized in more than 2,000 children, of varying ethnic and socioeconomic backgrounds.

The ASQ is also a parent report tool with 30-35 items. Completing the test can take parents usually 5 to 10 minutes, and providers usually only need 1 - 2 minutes to score the test.

The questionnaires cover five key developmental areas: communication, gross motor, fine motor, problem solving, and personal-social.

ASQ questionnaires are written at a 6<sup>th</sup> grade level and are available in English, Spanish and French.

The ASQ consists of 21 different questionnaires and scoring sheets appropriate for different ages between 2 and 60 months of age. Each questionnaire is valid for one month before and after the indicated age. So for example, the twelve month questionnaire can be used with children who are between 11 and 13 months.

#### ASQ: SE

The ASQ: SE is very similar to the ASQ for general development. The ASQ: SE is also available in Spanish and is written at a 5<sup>th</sup> grade reading level. The standardization sample for this tool included over 3,000 children from various socio-economic backgrounds.

The ASQ: SE offers a great way to assess a child's competency in a wide range of social and emotional topic areas. Some of the topics included are: self-regulation, communication, adaptive functioning, autonomy, compliance, affect, and interaction with others.

The parent fills out the ASQ: SE, like the ASQ for general development, with scoring and interpretation conducted by a professional.

# What about the Denver?

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**Title V Child Health Agencies should no longer use the Denver. Iowa Department of Public Health no longer endorses its use.**

The Denver (Denver Developmental Screening Test), while it was an innovation in its day, has not kept up with today's standards. It does not do a good job of picking out the kids with or without problems.

The Denver does a poor job of precisely what a developmental screening instrument is supposed to do: identify which children have problems (sensitivity) and which ones don't (specificity). (ASQ's sensitivity ranges from 70 to 90 percent and its specificity ranges from 76 to 91 percent. Denver's sensitivity is 68 percent and its specificity ranges from 43 to 80 percent).

The American Academy of Neurology and the Child Neurological Society "Because of the lack of sensitivity and specificity, the Denver-II (DDST-II) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) are not recommended for appropriate primary-care developmental surveillance."

## Title V Child Health Agency Information

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**Title V Child Health Agencies should no longer use the Denver.**

**Each agency has been provided with both ASQ tools in both English and Spanish (\$795.00 value) and a list of trainers that have been trained by the State to spread use.**

**Agencies should make arrangements to have staff trained in the use of this tool.**

**If your agency intends to use an alternate screening tool for any reason, please contact Meghan Wolfe to discuss the situation.**

**State Contact:**

**Meghan Wolfe 515-242-6167 [mwolfe@idph.state.ia.us](mailto:mwolfe@idph.state.ia.us)**

## Barriers to Implementing **1st Five** as Identified by Medical Practices

### **Lack of time:**

The implementation of the Child Health Development Record (CHDR) added, on average, three minutes to each well-child exam. In some instances, the surveillance form did not make the medical practices lose time, but in fact helped speed up the process.

### **Caregiver willingness to follow through with a provider referral:**

Since providers are viewed as a credible source by parents and caregivers, a physician's referral greatly improves the chance that a family will be more likely to follow through with that referral. As a part of the referral and follow up process, families should understand that they will be contacted by a **1st Five** care coordinator. To improve the chance of the receptiveness by the parent/caregiver when contacted by a **1st Five** care coordinator, medical staff should make it explicit that their referral is linked to **1st Five** care coordination services.

### **Lack of referral resources:**

Provider offices do not have time to keep up to date on information regarding children's and family's community based services. **1st Five** care coordinators are knowledgeable about locating resources that address the needs of children and families. **1st Five's** one-call referral source makes it easy for providers to connect patients with care coordinators who then link them to the appropriate intervention services. After one year of implementation, the project results demonstrate that for every one referral, the care coordinator identifies on average an additional three to five other services.

### **Lack of reimbursement:**

**1st Five** recognizes the lack of reimbursement remains a barrier to providing surveillance and screening. **1st Five** and other state projects are sharing this information with legislators and other key stakeholders. **1st Five** site coordinators are knowledgeable about current billing procedures for developmental surveillance and screening.

## What **1st Five**'s Commitment Means

Iowa's **1st Five** Healthy Mental Development Initiative is committed to helping to enhance patient care by promoting primary care provider use of standardized surveillance and screening tools to assess social-emotional development and family risk factors for young children. **1st Five** also links children and their families to community resources to improve access to appropriate follow-up care.

### **The 1st Five Healthy Mental Development Initiative site coordination team will:**

- Provide on-going training opportunities based on a self-assessment of training needs within the practice.
- Develop and maintain a streamlined referral process and care coordination for patient referrals for **all** public service and community resource needs.
- Provide notification of the referral results to participating practices.
- Maintain contact with provider office related to the effectiveness and efficiency of identification, referral, and follow up processes.
- Provide ongoing feedback on the composite patient referral data.
- Provide medical practices with focused technical assistance on Medicaid billing codes for needed screening and intervention services.
- Participate in an on-going statewide evaluation to aid in increasing quality improvement within the **1st Five** participating medical practices.





## 1st Five What Medical Provider Commitment Means

Commitment as a **1st Five** Healthy Mental Development Initiative provider paves the way for statewide spread of the initiative to strengthen partnerships between physician practices and public service providers to enhance high quality well-child care.

A primary care provider is viewed as a credible source, and plays an important role in the early identification of behavioral and developmental delays in children, as well as identifying family risk factors, such as family stress and caregiver depression, during routine well-child office visits.

### **A medical provider participating in the 1st Five Healthy Mental Development Initiative should:**

- Provide at least one physician and one office staff member to lead practice participation in all aspects of implementing **1st Five's** proposed standards and processes. One of these champions should participate in **1st Five's** community coalition. Other staff should participate in the **1st Five** project in accordance to their position.
- Utilize the Child Health and Development Record (CHDR) surveillance proposed by **1st Five** on all children birth through age five. The **1st Five** site coordinator will work with practice staff to integrate components of the CHDR into existing surveillance tools. Or at a minimum, integrate questions on social-emotional development (includes autism risk), caregiver depression and family stress during well-child visits.
- Select and utilize a validated screening tool for at-risk children and for all children at regular intervals as recommended by the American Academy of Pediatrics.
- Work with the **1st Five** team to develop and implement a process to facilitate the referral and treatment of children who are found to be at risk.
- Provide regular feedback about the standards and processes to the **1st Five** team and work with the team to make necessary adjustments.
- Participate in pre intake form and post project survey.



## 1st Five What Medical Provider Commitment Means

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- Select and utilize a validated screening tool for at-risk children and for all children at regular intervals as recommended by the American Academy of Pediatrics.
- Work with the **1st Five** team to develop and implement a process to facilitate the referral and treatment of children who are found to be at risk.
- Provide regular feedback about the standards and processes to the **1st Five** team and work with the team to make necessary adjustments.
- Complete a pre and post project implementation survey.



## 1st Five Physician and Office Champion

Physicians are viewed as a credible source of information regarding health care recommendations. This credibility can be a valuable tool to assist a parent/caregiver with understanding the importance of the medical referral and the link to **1st Five**. The more explicit medical staff can be about referring a parent/caregiver to **1st Five** based on their child's well-child exam, the easier it is for the **1st Five** care coordinator to establish contact with that parent/caregiver. Having committed physicians and staff at each practice helps ensure that the practice will be able to sustain the **1st Five** model.

It is critical to identify both a physician champion and an office champion at each provider site. One or both of these individuals should be invited to participate in the **1st Five** community coalition. The following outlines each role in further detail:

### Role of the *Physician Champion*:

- The physician champion directs the practice participation through overall support of the project, serving as the lead staff member on the project.
- The physician champion initially informs provider office staff of the commitment to enhancing well-child exams by linking to the **1st Five** initiative.
- The physician champion will ensure that the Child Health and Development Record (CHDR) forms are integrated into existing surveillance tools and used during well-child visits on all children birth through age five. Or at a minimum, the questions on social-emotional development (that includes autism risk), caregiver depression and family stress are added to well-child visits.
- Select and implement validated screening tools to be administered at the AAP-recommended well-child visits.
- The physician champion will complete pre intake form and post implementation survey.

### **Role of the Office Champion:**

- The office champion needs to have decision making power regarding office protocols.
- The office champion will be responsible for the project management tasks including:
  - Scheduling **1st Five** program trainings in conjunction with the **1st Five** site coordinator;
  - Ensuring that the process is in place for referring children and families to the local care coordinator;
  - Maintaining contact with the **1st Five** care coordinator on referral status;
  - Maintaining adequate supply of well-child surveillance forms, referral forms, and patient information materials;
  - Ensuring the completion of the pre intake form and post implementation survey by the provider (unless other arrangements are made for office champion to complete);
  - Communicating on a regular basis with the **1st Five** site coordinator based on a preferred method of communication (phone, fax, email);
  - Actively working with the **1st Five** site coordinator to troubleshoot problem areas and training needs, should they arise;
  - Delegating tasks to interested staff.

See the **1st Five Medical Provider Guide for Developmental Surveillance and Screening** in the Provider Materials section of this handbook for more information.



## 1st Five Training Resources

Consultation and training resources are available to help staff and medical providers understand and effectively implement the process of enhancing developmental surveillance and screening. **1st Five** can uniquely tailor training for each practice to improve patient outcomes and to make reimbursement for services easier for the practice. Possible training topics include:

### Surveillance

- Four key surveillance areas for the healthy mental development of young children: social, emotional and behavioral development; parental depression; family stress; and autism.
- The clinical implementation of surveillance for development; social, emotional and behavioral health; and family risk factors.
- Assessing for caregiver/parental depression during well child exams.

### Screening

- The clinical implementation of screening for: development; social, emotional and behavioral development; PDD/Autism; and parental risk factors.
- Overview of recommended developmental and autism screening tools and their use in a practice setting.

### Other Topics

- One-on-one technical assistance related to practical application issues such as:
  - Review of patient flow
  - Staffing well-child exams
  - Using results of enhanced surveillance
  - Problem solving with physicians on practice change concerns for surveillance, screening and referrals
- Linkages with local care coordination resources.
- How to discuss sensitive topics with parents (such as depression and/or family stress).
- How to deliver difficult news to parents.
- How to discuss culturally sensitive issues.
- Billing codes.

To schedule a consultation or training for your practice or to learn more about the **1st Five** Healthy Mental Development Initiative, contact the **1st Five** state coordinator at 1-800-383-3826 or the local **1st Five** site coordinator.



# Iowa EPSDT Care for Kids Health Maintenance Recommendations

## KEY

- To be performed
- To be performed at all visits
- ★ Screen at least once during time period indicated

S Subjective, by history;

[S] each visit during time period indicated

O Objective, by standard testing method;

[O] each visit during time period indicated

A Assess risk;

[A] each visit during time period indicated

		AGE																					See below ★			
		Infancy					Early childhood					Late childhood					Adolescence									
		2-3 <sup>1</sup> by 1 days	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	2 yr	2.5 yr	3 yr	4 yr	5 yr	6 yr	8 yr	10 yr	12 yr	14 yr	16 yr	18 yr	20+ yr				
History		● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●									
Physical exam		As part of each visit					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
Measurements		Weight/length: each visit through 18 mo; BMI each visit 24 mo and older					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
		Head circumference					● ● ● ● ● ● ●					● ● ● ● ● ● ●														
		Blood pressure					A					● ● ● ● ● ● ●					● ● ● ● ● ● ●									
Nutrition/Obesity prevention		Assess/educate					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
Oral health		Assessment - Dental history; Dental referral					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
(Oral health, 6 mo – 2 yrs: Referral to dental home if available; otherwise, assess oral health)							●					● ● ● ● ● ● ●					●									
Developmental and behavioral assessment		Surveillance					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
		Developmental screening: 9, 18, 24 or 30 mo					●					● ● ● ● ● ● ●					● ● ● ● ● ● ●									
		Autism screening: 18 & 24 mo										● ● ● ● ● ● ●														
Sensory screening		Vision					S					O					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
		Hearing					O					S					O					S				
Immunization		Perform an immunization review at each visit; administer immunizations at recommended ages, or as needed					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
Anticipatory guidance		Provided at every visit					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
PROCEDURES	Lipid screening						A					A					● ● ● ● ● ● ●					● ● ● ● ● ● ●				
	Hemoglobin/hematocrit	Perform once between 9-month and 12-month visits for children at risk; also annually for adolescents if risk factors are present					A					●					A									
	Hemoglobinopathy	Only once (newborn screen) and offered to adolescents at risk.					●																			
	Lead Screening	Assess and screen children at 12 mo. and 2 years of age; Assess and test high-risk children at 18 months, 3,4, 5 and 6 years.					●					A ●					A									
	Metabolic screening	The Iowa Newborn Screening Program tests for hypothyroidism, galactosemia, phenylketonuria, hemoglobinopathies, congenital adrenal hyperplasia, plus expanded metabolic screening.					●																			
	Sexually transmitted infections	Screen as appropriate. People with a history of, or at risk for, STIs should be tested for chlamydia and gonorrhea.																				A				
	Cervical Dysplasia Screening	Pap test at age 21																				A				
Tuberculin test		Testing is recommended for high risk groups, which include household members of persons with TB or others at risk for close contact with the disease; recent immigrants or refugees from countries where TB is common (e.g., Asia, Africa, Latin America, Pacific islands and former Soviet Union); migrant workers; residents of correctional institutions or homeless shelters; persons with certain underlying medical disorders. Children with HIV and incarcerated adolescents should be screened yearly.					A																			

<sup>1</sup> For newborns discharged within 24 hours or less after delivery.

★ Medicaid recommends and will reimburse for annual visits for older children and adolescents

<sup>1</sup> For newborns discharged within 24 hours or less after delivery.

★ Medicaid recommends and will reimburse for annual visits for older children and adolescents, but does not yet require them.

## What Do Providers have to Say About **1st Five**

“I love you [**1st Five**]. Don’t ever go away!” *Dr. David Williams, Methodist Plaza Pediatric Clinic, Des Moines*

“This is like a dream come true, we have needed something like this for a long time.” *Midwife, Knoxville*

“**1st Five** gives us additional support and enhances our patients’ continuity of care here at Knoxville Hospital Clinic. The [**1st Five**] staff are very knowledgeable about community programs and assist us in every way possible.” *James Haynes III, Interim Clinic Administrator, Knoxville Area Community Hospital Clinic*

“I’m learning a lot more about patients than I have before. I’m so glad we are doing this. It is actually saving us time.” *Dr. Rhonda Enserro, Walnut Creek Pediatric Clinic, Windsor Heights*

“Keep doing what you are doing. It is convenient, the feedback is a plus, and I am able to get to know my patients and families better.” *Physician*

“Once we begin using **1st Five** I hope it never goes away. It will be such a valuable service; it would be a shame if the funding source was lost. Our patients would be directly impacted.” *Physician*

“Now we have somewhere to send patients who have needs other than those we can treat for them. I have several in mind already!” *ARNP*

“The feedback process will be very useful, I will not have to wonder what is happening with the patient, and if they ever made it to their referral.” *Physician*

“The [CHDR] forms were good in identifying risk history and concerns from parents. Parents were glad to hear that providers were asking those [stress and maternal depression] kinds of questions and felt they were ‘cared about’.” *Pediatrician*

“The well-child visit is a “happy” time to build rapport. It really strengthens the connection to the family.” *Pediatrician*

“A lot of parents expressed that, ‘No one has ever asked me that before’.” *Pediatrician*

“[We told parents] ‘If we are taking care of our parents it is good for the children’ and that there are other resources in the community that can help.” *Registered Nurse, Pediatrics*

Healthy mental development in the first five years



“Many times you didn’t think about [the red flags] until the child wasn’t doing them. Now we are being more attentive to those types of problems.” *Family Physician*

“Maternal depression is an easy question to avoid because it deals with the mother or caretaker, but it is an important issue that affects children. The screening is a great way to begin a dialogue with parents. It is a start; doing something is better than doing nothing.” *Pediatrician*

“Thank you for all you do. It’s so good to hear when these families come back and state how much these services help. You are a breath of fresh air.” *Nurse, Medical Associates Pediatrics, Dubuque*

“**1st Five** staff are angels who were sent here to do the things that medical providers want to do, but aren’t able to.” *Dr. Andrea White, Ankeny Pediatrics*

“[**1st Five**] actually saves our doctors’ time.” *Kathy Karns, Office Manager, Methodist Plaza Pediatrics, Des Moines*

“Thank you for all of your help! I didn’t know where to send this family!”  
*Nurse, Clarke County Family Medicine*

“The staff was very excited after completing the training. They were glad to have somewhere to turn with the families that needed help.” *Office staff, South Central Iowa Medical Clinic*

"Before, there were so many roadblocks. This allows us to make one phone call, where they can use their resources, and it frees up our clinical assistants."  
*Dr. Stacey Neu, East Des Moines Family Care Center*

“I am very pleased with the **1st Five** program and try to use it for all my referrals. With this program I KNOW my patient's needs are tended to and the one step referral process is SO easy for my nurse - she appreciates it, too! I always receive timely feedback from [the **1st Five** coordinator] on the referral, and often other needs are met for the family because of the referral. The **1st Five** program helps me to give the best care to my patients and their family!”

*Dr. Colette Lothe, McFarland Clinic, Marshalltown*





## Ordering **1st Five** Materials

The materials in this section are available for you to use in implementing the **1st Five** model. The **1st Five** Provider Brochure, and **1st Five** Parent Brochure can be ordered by contacting the **1st Five** state coordinator at 1-800-383-3826. Electronic versions of the **1st Five** Medical Provider Guide for Developmental Surveillance and Screening, the **1st Five** Provider Protocol Flow Chart, and the Template Letter to Providers, as well as the Template Letter to Parents, can also be requested by calling the **1st Five** state coordinator. In addition, the **1st Five: A Bridge between Primary Care and Community Resources** flipbook and Developmental Surveillance and Screening Tools: A Medical Practice Guide Brought to you by **1st Five** or pocket guide can also be requested.

Additionally, more information for professionals and parents, and electronic links to **1st Five** materials are available from the **1st Five** website at [www.idph.state.ia.us/1stfive](http://www.idph.state.ia.us/1stfive).





## Maternal Depression Screening Talking Points for 1st Five Practices

Why should you be concerned with maternal perinatal depression?

*Maternal depression also negatively affects children.*

The role of a pediatrician or physician caring for an infant or young child is to make sure the child is thriving in an adequate, nurturing environment.

Maternal depression affects 2 out of 10 women who have children, and is a serious condition that can have long-lasting effects on children. Primary care providers play a critical role in identifying mothers at risk for postpartum depression and ensuring that they receive prompt and effective care.

### **Behaviors commonly associated with depressed mothers**

- Less responsive to baby's cues
- Less awareness of baby's needs
- Reduced ability to communicate range of emotions
- Reduced care and stimulation of baby
- Less interactive behavior
- Less empathy
- Less likely to obtain preventive health care for baby

*\*In some instances, maternal depression may have no effect on parenting*

*Sensitive mothering constitutes being aware of an infant's signals.*

Sensitive interactions are associated with the development of secure attachments, and secure attachments are associated with the ability to form healthy relationships throughout life. Depressed mothers display one of two patterns, flat affect- low activity level and lack of contingent responding, or alternating disengagement and intrusiveness. The prenatal or postpartum periods are not times for non-psychiatric clinicians to ignore depression screening, which is routinely recommended for patients seen in primary care settings.

### **Effects of untreated postpartum depression on infants**

- Difficulty in developing trusting relationships
- Impeded growth during the first year of life
- Inactivity or hyperactivity
- Irritability
- Irregular sleep and feeding behaviors
- Lifelong decreased ability to handle stress

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Even infants who cannot speak with language can communicate clearly with their mothers. Infants of depressed mothers are less likely to have a secure attachments and more likely to display an insecure attachment compared to infants of non-depressed mothers. Data show children of depressed mothers may have difficulty developing trusting relationships, thus negatively affecting social and emotional development. Children of depressed mothers are six to eight times more likely to have a depressive disorder, and five times more likely to develop a conduct disorder. These children also display deficits in academic and social skills.

<b>Risk factors associated with an increased risk of depression after childbirth</b>
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- |   |
|---|
| <ul style="list-style-type: none"><li>• Previous history of depression or postpartum depression</li><li>• Family history of depression</li><li>• Domestic violence</li><li>• Substance abuse</li><li>• Lack of social support</li><li>• Environmental factors (eg. lack of food, inadequate income or housing conditions)</li></ul> |
|---|

It is important for primary care providers to be especially alert to the possibility of depression among patients who have a previous history or family history of depression, lack social support, or have environmental factors related to inadequate finances.

The presence of one or more of these factors does not indicate that a woman will experience depression, nor does their absence mean that a woman is not at risk for depression. Therefore, it is extremely important that ALL pregnant mothers and new mothers are screened for depression, regardless of whether risk factors are apparent.

### **The Importance of Screening**

Maternal depression is a treatable condition, and treatment improves the short- and long-term effects for both mothers and their children. Routine screening will help to reduce the stigma associated with mental health issues. Screening is simple, convenient, rapid, and reimbursable.



## Screening during Well-child visits

The American Academy of Pediatrics and the American Academy of Family Physicians recommend screening for maternal depression. Due to the frequency of recommended well-child visits, the primary care provider is put in a unique position to monitor both the baby's growth and development and the mother's emotional well-being.

Formal screening provides a reliable way to detect postpartum depression, since many women are reluctant to admit that they are depressed. A recent study showed that 80 percent of mothers were comfortable with the idea of being screened for postpartum depression, but less than half of primary care practices currently screen. The Edinburgh Postnatal Depression Scale is one standardized screening tool for medical practices to use.

## Barriers to Screening

Although perinatal depression affects 2 out of 10 mothers, recent surveys of healthcare providers suggest that the condition remains under-recognized and under-treated. A recent American Academy of Pediatrics study on pediatricians' attitudes about maternal depression indicated that 57 percent of respondents reported feeling responsible for recognizing maternal depression.

However:

- 73% reported insufficient time for taking the mother's history
- 64% felt they did not have enough training on the topic to diagnose or counsel the mothers
- 48% felt they had insufficient knowledge of treatment options

Seventy percent of family physicians said that they always or often screened for postpartum depression at the postpartum examination, while 46 percent did so at well-child exams. However, only 22 percent overall reported using validated screening tools, meaning the majority of providers who said they screened for postpartum depression did so with either unvalidated tools or informal assessments.

Several studies have confirmed that informal or no assessment of potential postpartum depression is ineffective, resulting in less than half of cases or potential cases discovered through formal screening.

Results published in *Pediatrics* showed that the detection rate for postpartum depression increased from 5% to 20% after formal screening was incorporated into well-child visits, and referrals increased from 0.2% to 3.6%.

For more research data and perinatal depression support information, see the Caregiver Depression of this handbook.



## Healthy mental development in the first five years



### ***About 1st Five: A Bridge between Primary Care and Community Resources***

This is a program guide that can be used as a presentation resource for 1<sup>st</sup> Five staff during provider visits. It is designed to be presentable in entirety in ten minutes or under to provide an overview of the 1<sup>st</sup> Five program.

The guide's format is stationary and can be placed on a meeting room table with each side tailored to a different audience. One side is for primary care providers and clinic staff. The other is for 1<sup>st</sup> Five site coordinators or presenters. Site coordinators will be able to find the full list of intake questions on their side such as "Does someone provide care coordination in your practice?" and "How will the children and families in your practice benefit?"

The guide also includes information on childhood development and how family risk factors such as caregiver depression and toxic stress can play a role in children's adverse long term health outcomes. It covers the 1<sup>st</sup> Five model, the general services and resources 1<sup>st</sup> Five refers to and Iowa related statistics. The primary care provider side is visual, containing a mixture of information and pictures.

### ***Overview of 1<sup>st</sup> Five, pg. 1-2:***

The headings what, why, who and how give an overview of 1<sup>st</sup> Five. The central mission of 1<sup>st</sup> Five's is to enhance high-quality well-child care. The important role and work of physicians and the importance of performing developmental surveillance and screening to identify social-emotional delays, developmental delays, family stress, parental depression and autism is highlighted.

### ***The Early Childhood Period, pg. 3-4:***

This page discusses the early childhood period as being a critical time during which children develop social, emotional and mental capacities that have a lifelong impact. Interventions are the most effective in the early years.

## Healthy mental development in the first five years



### ***Children are Eluding Early Detection, pg. 5-6:***

This page gives some Iowa specific statistics on developmental, behavioral and social delays and that many children with delays are not detected prior to starting school. In fact, of those at risk of developmental delays, only 50% are identified before they enter school. It is also noted that 71% of pediatricians use observation of development to screen children. By this method, only 30% of young children with developmental concerns are identified.

#### Intake questions:

- How many patients are seen in your practice on an annual basis?
- Approximately how many children ages 0-5 does your practice serve?
- How many healthcare providers? Doctors? Nurses? PAs?

### ***The Effect of Toxic Stress on the Child's Developing Brain, pg. 7-8:***

Research shows that toxic stress and the lack of responsive caregiving can lead to disparities in learning and behavior. Toxic stress can also come in the forms of extreme poverty, neglect, abuse, trauma or maternal/caregiver depression. Providers will be able to see a picture of neural connections at birth, 6 years, and 14 years, with the neural connections being significantly denser and more developed at 6 years of age signifying that the majority of the brain has already formed by this age. In fact, 90% of the brain is formed by age 5.

### ***1<sup>ST</sup> Five Partnership Model, pg. 9-10:***

The 1<sup>st</sup> Five Partnership Model is discussed and the following intake question can be found:

- How did you become aware of the 1<sup>st</sup> Five Healthy Mental Development Initiative?

### ***What 1<sup>st</sup> Five Can Do for YOUR Medical Practice, pg. 10-11:***

What providers who work with 1<sup>st</sup> Five can expect out of the collaboration are discussed. Providers will learn that 1<sup>st</sup> Five links children and families to community resources and services, promotes developmental surveillance and screening tools, helps integrate those tools into their practices and provides regular feedback on patient progress and referrals.

## Healthy mental development in the first five years



### Intake

#### questions:

- Do you currently perform surveillance in your practice? If no, why not? If yes, what standardized tool do you use? Is this tool imbedded in your practice's Electronic Medical Record (EMR)? If yes, when do you currently perform surveillance?
- What are or were the barriers/concerns regarding the implementation of developmental surveillance in your practice (cost, lack of time, lack of staff, no referral sources in community, etc).
- Do you currently perform screening in your practice? If no, why not? If yes, what standardized tool do you use (ASQ, Denver II, etc)? Is this tool embedded in your practice's Electronic Medical Record (EMR)? If yes, when do you currently perform screening?
- What about barriers of developmental screening? Does your practice currently ask questions during office visits addressing family stress, parental depression, autism or adverse childhood experiences? If yes, do you use standardized questions/tools? If yes, which standardized questions/tools do you use? When are they asked? If no, what is your plan for integrating these types of questions into your practice?

#### ***Recommendation by the American Academy of Pediatrics, pg. 10-11:***

The American Academy of Pediatrics screening recommendations at the time periods of 9 mo, 18 mo, 24 or 30 month are noted. In addition, screening for autism should be conducted with an autism-specific tool at 18 and 24 month well-child visits.

#### ***1<sup>st</sup> Five's Single Point of Contact, pg. 12-13:***

The convenience of a single point of contact for providers is highlighted. When contacted by a primary care provider, a 1<sup>st</sup> Five care coordinator then serves children and families with their expert knowledge in available community resources. Families are linked to appropriate community services and regularly follow up with the provider on the patient progress. Care coordinators also help arrange medical transportation and integrate healthy mental development into their everyday work with families.

#### Intake questions:

- Does someone provide care coordination in your practice? If yes, who?
- Has your practice worked with a community-based care coordinator? If yes, who?
- Describe your experiences with care coordination? Positive? Negative?
- Do you consistently receive feedback from your referral sources?



## Healthy mental development in the first five years



### ***Possible Reasons for a Provider Referral into 1<sup>st</sup> Five, pg. 13-14:***

Reasons for 1st Five referrals may be developmental concerns, increased risk of developmental delay, social or behavioral concerns, caregiver depression, parent or family stress, hearing or speech concerns, missed appointments, resource needs and other health-related issues. For every provider referral to 1<sup>st</sup> Five, an additional 3 referrals are identified once the care coordinator starts working with the family.

#### Intake Question

- What referral sources do you currently use?

### ***Possible 1<sup>st</sup> Five Services and Resources, pg. 15-16:***

Some examples of community resources 1st Five refers to are given: dental care services, mental-health services, Area Education Agencies, Early Access Part C, health insurance services, home visiting programs, case management, parenting support, child development information and other resource needs.

### ***1<sup>st</sup> Five Success Story, pg. 17-18:***

Carrie is one example how a physician referral into 1<sup>st</sup> Five led to additional referrals that also helped the child's family. 1<sup>st</sup> Five was able to help the mom access necessary resources for her current pregnancy and help the family with heating, food and transportation to medical appointments when the care coordinator started their direct work with the family. The family's stress levels decreased and Carrie's condition improved as a result.

#### Intake questions:

- Has your practice decided to join the 1st Five Healthy Mental Development
- Initiative? Why?
- How do you think your practice will benefit?
- How will the children and families in your practice benefit?
- Have you identified needs for children/families but were not aware of area resources to address those needs? If yes, what needs?
- Is your practice a member of the Iowa Health Information Network (IHIN)?
- What training or support related to 1st Five, screening or healthy mental development would your practice find useful?
- What are your concerns or questions regarding joining the 1st Five Initiative?
- What is the best way to maintain ongoing communication? Who is the primary contact?

## Healthy mental development in the first five years



### ***Developmental Surveillance and Screening Tools: A Medical Practice Guide brought to you by 1<sup>st</sup> Five Healthy Mental Development Initiative***

Primary care providers play a crucial role in supporting optimal social-emotional development in children as well as healthy motor development. Nearly all families encounter primary health care in a child's first five years of life. During these early visits, timely surveillance and screening is critical to identify children who have delays in general and social-emotional development or behavioral development. Children who are screened during these early well-child visits are connected to needed services sooner, improving their health outcomes.

A majority of physicians and other primary care providers rely solely on the observation method to evaluate a child with developmental delay. Research has shown that by the observation-only method, just 30% of children with developmental disorders are being identified before age five. Furthermore, only 50% of children at risk today for developmental delays are identified before they enter school. By promoting developmental surveillance and screening through **1st Five**, more children at risk for developmental delay can be identified during early well-child visits when interventions are the most effective.

One of the goals of *Developmental Surveillance and Screening Tools: A Medical Practice Guide brought to you by 1<sup>st</sup> Five* is to promote the use of surveillance and screening by primary care providers in the birth to age five population. The guide provides information on standardized surveillance and screening tools that are supported by the Iowa Department of Public Health, the American Academy of Pediatrics, as well as follow Iowa's EPSDT Care for Kids Health Maintenance Recommendations.

### **Highlights**

The guide includes information on developmental surveillance and screening tools as well as provides testing timelines based on EPSDT Care for Kids Health Maintenance Recommendations. On page three in the guide, providers can glance at a table that outlines when surveillance and screening should be conducted, when caregiver depression should be administered based on a child's age, when to screen for autism as well as when to conduct a psychosocial/behavioral assessment.

## Healthy mental development in the first five years



Each screening and surveillance tool is covered in a detailed two pages with the information divided into four easy-to-read sections: *General Overview*, *Administer for Population/at Age*, *How it Works* and *Time to Administer & Evaluate*. Billing information and CPT codes are also found in the guide.

Surveillance tools: Bright Futures and Iowa Child Health and Development Record (CHDR).

Validated screening tools: Ages & Stages Questionnaires 3<sup>rd</sup> Edition (ASQ-3), Ages & Stages Questionnaires: Social Emotional (ASQ:SE), Edinburgh Postnatal Depression Scale (EPDS), The Patient Health Questionnaire (PHQ-9) and the Modified Checklist for Autism in Toddlers (MCHAT-R/F).

### Surveillance Tools

#### 1. **Bright Futures:**

- The American Academy of Pediatrics (AAP) supports Bright Futures for delivery of preventative services for children. The resources in Bright Futures incorporate children's mental, physical and emotional aspects of well-being and its flexible resources allow physicians to conduct comprehensive surveillance, evaluate patients as well as track a child's progress.
- The forms can be administered in the prenatal months to 21 years of age. Bright Futures surveillance forms should be administered at every well-child visit.
- Forms available online at: [www.brightfutures.aap.org/tool\\_and\\_resource\\_kit.html](http://www.brightfutures.aap.org/tool_and_resource_kit.html).
- Billing: There is no separate billing for Bright Futures surveillance, however there are recommended elements in Bright Futures that are billable.

#### 2. **Iowa Child Health and Development Record (CHDR):**

- This standardized universal surveillance tool is also equipped with referral resources and serves as a guide and as a documentation resource for providers during a child's health maintenance visit. The forms identify risk factors pertaining to a child's nutrition, family stressors and caregiver depression and also help identify risks relating to social-emotional concerns and developmental red flags. The results also inform the family or caregiver of appropriate interventions and referrals.
- Forms are available for the following age intervals: 1-4 weeks, 2, 4, 6, 9, 12, 15 and 18 months, 2 years, 30 months, 3, 4, 5, 6, 7-8, 9-10 and 11-17 years.

## Healthy mental development in the first five years



- Forms are filled out by staff and provider in the exam room
- There is no scoring with the CHDR. The forms are available for download at no cost from the Iowa Care for Kids EPSDT provider website.
- Billing: Iowa CHDR is billed out as part of the well-child exam.

### Screening Tools

#### 1. Ages & Stages Questionnaires 3<sup>rd</sup> Edition (ASQ-3):

- This highly valid and reliable family-friendly parent completed screening tool identifies developmental delays between 1 month and 5 ½ years. It covers the areas of communication, gross motor, fine motor, problem solving and personal-social in its 21 questionnaires that each consist of about 30 items.
- Questionnaires are available for the recommended screening periods of 9, 18, 24 or 30 month as well as for the months of 2, 4, 6, 8, 10, 12, 14, 16, 20, 22, 27, 33, 36, 42, 48, 54 and 60 months.
- Questionnaires take 10-15 minutes for parents to complete and 2-3 minutes to score.
- Billing: CPT code 96110 should be used.

#### 2. Ages & Stages Questionnaires: Social Emotional (ASQ:SE):

- This first level research based screening tool identifies children at risk for social and emotional difficulties identifying those who would benefit from a more in depth evaluation and/or preventative intervention. The questionnaires, each containing of 30 items, reflect specific developmental milestones and have a focus on the following areas: adaptive functioning, autonomy, self-regulation, communication, compliance, affect and interaction with others.
- Questionnaires are available for the recommended screening intervals of 18 and 24 or 30 month. If a concern is identified, questionnaires are also available for 6, 12, 36, 48 and 60 months.
- The questionnaires take 10 minutes for a parent or caregiver to complete and 2-3 minutes for healthcare professionals to score.
- Billing: Use CPT code 96127

#### 3. Edinburgh Postnatal Depression Scale (EPDS):

- This 10 question self-reported tool for postpartum women screens for the presence of depression in the perinatal period. The patient is asked to rate 1 of 4 possible responses that comes the closest how she or he has been feeling in the last 7 days. It can also be used to screen fathers for depression.

## Healthy mental development in the first five years



- The EPDS can usually be completed and scored in less than 5 minutes.
- If suicidal ideation is indicated, an immediate referral should be made for follow-up.

#### 4. **The Patient Health Questionnaire (PHQ-9):**

- PHQ-9 is an instrument that can be used to screen, diagnose, monitor and measure depression severity. It rates the frequency of symptoms and incorporates depression diagnostic criteria. Question 9 on PHQ-9 screens for the presence and duration of suicide ideation.
- Administration should be to males and females 18 years and older. It can also be administered in adolescent caregivers.
- Validated for use in all caregiver populations.
- Takes less than five minutes for administration and evaluation.
- Billing: CPT code 96127

#### 5. **Modified Checklist for Autism in Toddlers (MCHAT-R/F):**

- This developmental screening tool identifies children who may benefit from a more thorough autism evaluation. It is designed to be completed by parents or guardians
- Not to be used as a diagnosis tool. Children at risk should be referred for a follow-up and a more in depth evaluation
- Should be administered at the 18 and 24 or 30 month visit
- If a child screens positive, select only the Follow-Up items based on which items the child failed on the MCHAT-R/F
- If a child has failed two items on the Follow-Up, the interview is a positive screen.
- MCHAT-R/F takes about 5-10 minutes to administer and evaluate
- For scoring, all items on the MCHAT-R/F except question 2, 5 and 12, the response "NO" indicates ASD risk; for items 2, 5 and 12 "YES" indicates ASD risk.
- If a child is younger than 2 years, screen after their second birthday. No further action required unless surveillance indicates risk for ASD.
- For medium risk, the Follow-Up (second stage of MCHAT-R/F) should be administered. If score remains at 2 or higher, the child has screened positive and should be referred for further evaluation. If score on Follow-Up is 0-1, child has screened negative and no further action is required unless surveillance indicates risk for ASD.
- For high risk, it is acceptable to bypass the Follow-Up and refer immediately for evaluation.
- Billing code 96110 should be used.

Healthy mental development in the first five years



[SITE COORDINATOR CONTACT  
INFO]

[DATE]

[CONTACT NAME  
PRACTICE ADDRESS]

Dear [PHYSICIAN OR OFFICE MANAGER]:

You provide a critical service to the children and families in [COUNTY]. The **1st Five** Healthy Mental Development Initiative would like to help you and the families you serve by providing care coordination assistance in linking families to local services, based on your referral.

Iowa's **1st Five** Healthy Mental Development Initiative is here to help you serve young children. **1st Five** is a legislatively funded program that builds partnerships between physician practices and public service providers to enhance high-quality well-child care. As your public health partner, we are inviting you to be a part of an innovative team with providers across the state working to enhance their delivery system for young children and their families. More than **80** medical practices in Iowa are currently involved. The **enclosed materials** outline the initiative for medical practices.

We are offering the opportunity for you to participate in this initiative and in turn, we will be available to your patients and their families as community resources at no cost to you.

Sincerely,

[SITE COORDINATOR]

## Have you ever...

...had a family who is continually missing or rescheduling well-child visits due to family stress or challenges such as transportation?

...been concerned about a parent or caregiver's stress or possible depression, but not been able to ask due to lack of time, screening tools, or referral resources?

...made a referral and been left wondering, "Did they make the call?" or "What was the outcome?"

...been concerned that parental issues may be negatively impacting the current and future social and emotional development of a child you are seeing?

**1st Five can help!** The 1st Five Healthy Mental Development Initiative builds a support system for families between medical practices, child health agencies and a wide variety of local services.

### Components of a well-child exam

The primary goal of routine preventive health care is to ensure that a child is developing normally, which includes social and emotional development.

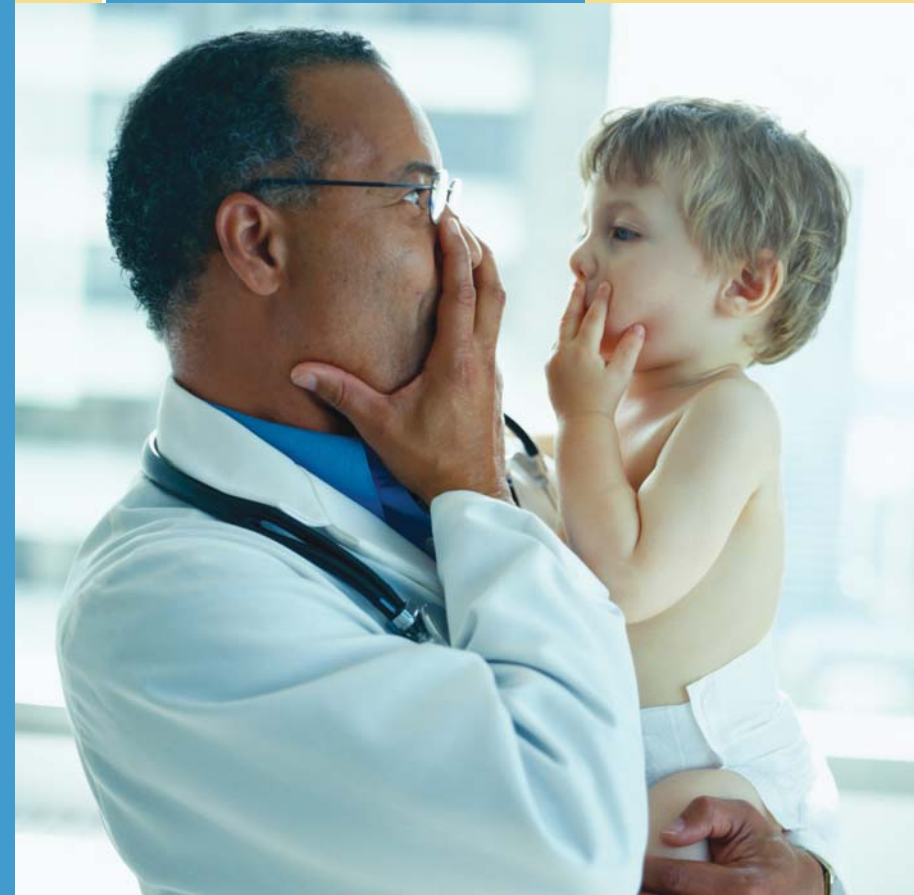
- Health history ■ **Developmental screening**
- **Social history** (*including family stress and parental depression*)
- Vision/hearing screening
- Complete physical exam, including dental screening
- Lab tests, including lead screening ■ Immunizations
- Advice on what to expect and how to keep your child healthy

For more information about the **1st Five** Healthy Mental Development Initiative, contact your local agency as listed on the insert or contact the state coordinator at **1-800-383-3826**.

For more information on the recommended early childhood standardized surveillance tools, go to [www.iowaepsdt.org](http://www.iowaepsdt.org).



Healthy mental development  
in the first five years



## 1st Five Information for Health Care Providers



## Primary Care Physicians and Social/Emotional Development

Over 90% of Iowa families take their children to a primary care provider before age 5. Primary care providers have a unique opportunity to play an important role in early identification and treatment for children’s developmental issues.

In the first years of life, children rapidly develop the social and emotional capacities that prepare them to be self-confident, trusting, empathetic, intellectually inquisitive, competent with language, and capable of relating well with others. With the proper tools, a primary care provider can identify risk factors for poor social and emotional development.

### Research on early child development...

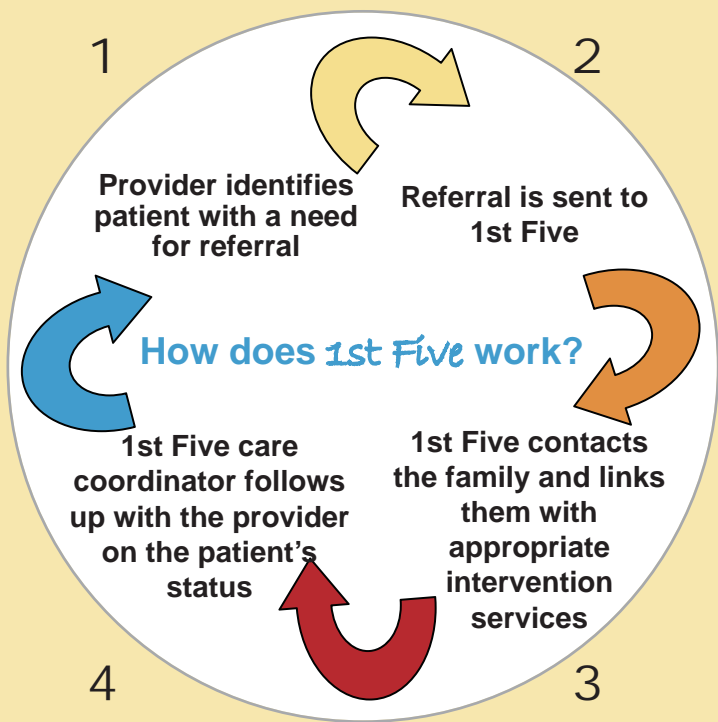
- Nationally, 71% of pediatricians use only observation of development to screen children; however, clinical observation used in isolation identifies only 30% of young children with developmental concerns.
- While 15-18% of school-aged children have a developmental or behavioral disability, less than 50% are identified prior to starting school. If not identified early, these children are at risk for school failure.
- The foundations for school success, learning and general well-being are established before a child enters kindergarten.
- Children of depressed mothers are 6-8 times more likely to have a depressive disorder and five times more likely to develop a conduct disorder.
- Emotional development in young children is now known to be as important as physical, cognitive and language development.

## What is 1st Five?

Iowa’s 1st Five Healthy Mental Development Initiative builds partnerships between physician practices and public service providers to enhance high quality well-child care. 1st Five promotes the use of validated developmental surveillance tools that support healthy mental development for young children.

By using a surveillance tool, which includes social/emotional development and family risk factors, for all children, providers are able to identify children at risk for developmental issues that would play out later in life if left untreated.

1st Five has been legislatively funded since 2006. Seven child health agencies are implementing 1st Five, covering 17 counties and 60 medical practices.



## What can 1st Five do for medical practices?

Promote primary care provider use of validated surveillance and screening tools to assess social and emotional development and family risk factors.

Help providers integrate these tools into their practices.

Link children and families to community resources and services to access appropriate follow-up care.

Provide feedback on the referral process for each child and family.

## What can medical practices do?

Use validated surveillance tools for all children birth to five at well-child visits.

Use appropriate developmental screening tools at ages recommended by the American Academy of Pediatrics.

Identify children at risk as early as possible.

Refer to local child health agency for early intervention services and community resources.



*Making a  
Difference  
One Family  
at a Time*





# Medical Practice Guide for Enhancing Developmental Surveillance and Screening

## READY?

### Preparing Yourself and Colleagues

#### *Step 1: Prepare Yourself and Your Staff*

1. Understand the difference between developmental surveillance and screening.

**Surveillance - All children receive surveillance at every well-child visit**, as recommended by the American Academy of Pediatrics (AAP), to recognize those who may be at risk for developmental delays. Surveillance is a consistent process at each encounter. Surveillance is a structured, objective, recordable process that is incorporated into every child health care encounter and identifies all children at risk. This includes assessing caregiver stress and depression and social-emotional development. [See pages 20-21 for surveillance tools or [www.iowaepsdt.org](http://www.iowaepsdt.org) for Iowa Child Health and Development Record (CHDR) forms.]

**Screening – At specific AAP-recommended time periods or whenever a concern is identified**, the provider uses a validated developmental screening tool to identify children who may be at risk for a disorder or may need further evaluation. (See pages 12-17 for screening recommendations and tools.) Screen whenever surveillance suggests that a child may be at risk in any domain such as general development, socio-emotional and behavioral development. Examples of screening tools would include Ages and Stages (ASQ or ASQ:SE) or the Modified Checklist for Autism in Toddlers (MCHAT). It does not include the CHDR – a surveillance tool.

- This requires more time, but can be reimbursed under code 96110. Medicaid, *hawk-i*, and many private insurance plans are reimbursing for developmental screening under this code. (See pages 18-19 for more billing information.)

2. Consider possible new resources or referrals for issues revealed. Your local Title V child health agency or *1st Five* site coordinator is an excellent place to start. (See pages 9-11 for contact information.)
3. Be prepared for the human side of change.
  - Change can be difficult; benefits must be made clear, and perceived barriers must be discussed.
4. Obtain explicit support from leaders.
5. Assess training needs. (See page 7 for available training topics.)

## ***Step 2: Identify a provider champion and an office champion***

### **Role of the Provider Champion:**

- Directs practice participation through support of the project
- Initially informs staff of commitment to enhancing well-child visits
- Ensures that the surveillance tools are integrated into well-child visits
- Completes a 10 minute office assessment survey before and after making changes

### **Role of the Office Champion:**

- Needs decision making power re: office protocols
- Responsible for project management tasks:
  - Coordinates logistical details for implementation
  - Conducts assessment of staff training needs
  - Schedules office trainings
  - Determines effective referral process with local child health agency
  - Maintains on-going contact with local care coordinator of child health agency
  - Maintains adequate supply of:
    - well-child surveillance forms (if no electronic medical records)
    - referral forms
    - patient information materials
  - Delegates tasks to interested staff

## **SET.**

## **Considerations for Surveillance, Screening, Referral and Follow-up**

### ***Step 1: Surveillance***

1. Communicate with staff about new procedures for surveillance.
  - Familiarize staff with the new forms and *what is an automatic screening or referral*.
  - Provide consistent information for all staff to give parents about the purpose of assessment and how the information benefits their child's care.

2. Determine when the new forms will be filled out.
  - ☐ Completed by family in office waiting room. (See pages 20-21 --available by contacting the *1st Five* state coordinator at 1-800-383-3826)
  - ☐ Completed by staff in exam room. (CHDR forms available from <http://www.iowaepsdt.org>)
  - ☐ Completed by provider in exam room. (CHDR forms available from <http://www.iowaepsdt.org>)
3. Determine who will discuss the results with the family, identify intervention options, and explain their importance.
  - ☐ RN
  - ☐ Nurse Practitioner
  - ☐ Physician Assistant
  - ☐ Provider

## ***Step 2: Screening***

1. New procedures for screening—seek input from staff
  - Select screening tool. The Iowa Department of Public Health supports the Ages and Stages Questionnaire (ASQ), Ages and Stages Questionnaire S-E (ASQ-SE) [<http://www.agesandstages.com/>], and the Modified Checklist for Autism in Toddlers (M-CHAT) [<http://www.firstsigns.org/screening/tools/rec.htm>]. A complete list of tools can be found at [www.iowaepsdt.org](http://www.iowaepsdt.org). (See pages 15-17 for table of screening tools.)
  - Organize materials to be easily accessed as needed.
  - Provide consistent information for all staff to give parents about the purpose of the screening and assessment and how the information benefits their child's care.
  - Determine the intervals for administering the screening tool. (AAP recommends developmental screenings at 9, 18, and 24 or 30 months and screening for autism at 18 and 24 months or whenever a parent or provider concern is expressed.) (See pages 12-14 for Iowa *Care for Kids* recommendations.)
  - Determine how you will identify patients who should be screened (e.g., flagging charts, incorporating a reminder system into patient appointments).
  - Determine office protocol for administering screening:
    - ☐ Completed by family in office waiting room.
    - ☐ Completed by staff in exam room.
    - ☐ Completed by provider in exam room.
2. Who will distribute and score the screening tool?
  - ☐ Office staff role: \_\_\_\_\_
  - ☐ Medical Assistant role: \_\_\_\_\_
  - ☐ RN role: \_\_\_\_\_
  - ☐ Nurse Practitioner role: \_\_\_\_\_
  - ☐ Physician Assistant role: \_\_\_\_\_
  - ☐ Physician role: \_\_\_\_\_
  - ☐ Other: \_\_\_\_\_
3. Test out on a few patients/families before implementing throughout the practice

- Did this tool uncover new and important parental concerns?
- How did the parents react to providing this information?
- Do I need more information or training to make this a better interaction?
- How could we improve the flow of providing the tool to the parent?

4. Determine what to do with completed screenings

- Store? If so, where?
- How to incorporate information from the screening into future care?

**Step 3: Referral and follow up**

1. Identify how to link patient referrals with community resources.

- We suggest contacting your local Title V child health care coordinator or *1st Five* site coordinator via fax back form or phone call. (See pages 10-11 for your local contact information.) Care coordinators link families with intervention services, monitor progress, and update providers on status of referrals.

2. Determine who should handle the fax back forms:

- ☐ Office Manager
- ☐ Receptionist
- ☐ Referring RN
- ☐ Referring Physician Assistant
- ☐ Referring Physician
- ☐ Other: \_\_\_\_\_

**Tips on How to Deliver Difficult News.**

- Plan ahead.
- Start with observations, questions, or concerns by the child's parent.
- Share your observations, frankly but compassionately.
- Start with positive comments on what the child is doing well before sharing concerns.
- State that further screenings and follow up are critical to ensuring the best possible positive outcome for their child.
- Provide information on referral sources or explain that a care coordinator will be contacting them. Have parent sign the release of information form.
- Emphasize importance of following up on the referral.

**GO.**  
**Monitoring Progress**

1. Ask for patient feedback during visits.
2. Ask for staff feedback.

### 3. Assess results.

## *Supplementary Resources*

American Academy of Pediatrics. The National Center of Medical Home Initiatives for Children with Special Needs. (2008). Developmental Surveillance and Screening Provider Information. <http://www.medicalhomeinfo.org/screening/index.html>

Commonwealth Fund. Improvement Checklist: Steps to Using Screening and Surveillance in Your Office. Retrieved 2008, from [http://www.commonwealthfund.org/usr\\_doc/Improvement\\_Checklist-Steps\\_to\\_Screening\\_and\\_Surve.pdf](http://www.commonwealthfund.org/usr_doc/Improvement_Checklist-Steps_to_Screening_and_Surve.pdf)

Centers for Disease Control and Prevention. Department of Health and Human Services. (2005). Developmental Screening for Health Care Providers. Retrieved 2008, from [http://www.cdc.gov/ncbddd/child/screen\\_provider.htm#chart](http://www.cdc.gov/ncbddd/child/screen_provider.htm#chart)

Early & Periodic Screening, Diagnosis & Treatment Care for Kids. [www.iowaepsdt.org](http://www.iowaepsdt.org)

The Commonwealth Fund. (2006). A Practical Guide for Improving Child Developmental Services. Module 2: Developmental Screening and Surveillance. Retrieved 2008, from [http://www.commonwealthfund.org/innovations/innovations\\_show.htm?doc\\_id=372065](http://www.commonwealthfund.org/innovations/innovations_show.htm?doc_id=372065)

American Academy of Pediatrics. (2010). Tools for Working with Practices to Improve Preventive Care Using Bright Futures. Retrieved 2010, from [http://www.brightfutures.aap.org/clinical/training\\_and\\_implementation\\_materials.html](http://www.brightfutures.aap.org/clinical/training_and_implementation_materials.html)



# Medical Practice Guide for Developmental Surveillance and Screening

## APPENDICES

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Spanish Form	

Consultation and training resources are available to help staff and medical providers understand and effectively implement the process of enhancing developmental surveillance and screening. *1st Five* can uniquely tailor our training for your practice needs to improve patient outcomes and to make reimbursement for services easier for your practice. Possible training topics include:

#### Surveillance

- Four key surveillance areas for the healthy mental development of young children: social, emotional and behavioral development; parental depression; family stress; and autism.
- The clinical implementation of surveillance for development; social, emotional and behavioral health; and family risk factors.
- Assessing for caregiver/parental depression during well child exams.

#### Screening

- The clinical implementation of screening for: development; social, emotional and behavioral development; PDD/Autism; and parental risk factors.
- Overview of recommended developmental and autism screening tools and their use in a practice setting.

#### Other Topics

- One-on-one technical assistance related to practical application issues such as:
  - Review of patient flow
  - Staffing well-child exams
  - Using results of enhanced surveillance
  - Problem solving with physicians on practice change concerns for surveillance, screening and referrals
- Linkages with local care coordination resources.
- How to discuss sensitive topics with parents (such as depression and/or family stress).
- How to deliver difficult news to parents.
- How to discuss culturally sensitive issues.
- Billing codes.

To schedule a consultation or training for your practice or to learn more about the *1st Five* Healthy Mental Development Initiative, contact the *1st Five* state coordinator at 1-800-383-3826 or your local *1st Five* site coordinator (see pages 10-11).

**EPSDT Care for Kids Program:**

EPSDT is the Early Periodic Screening, Diagnosis, and Treatment program for children birth to twenty-one years enrolled in Medicaid. The focus of this program is to assure that eligible children receive preventive health care services including oral health care. In Iowa, the EPSDT program is called *Care for Kids*. EPSDT *Care for Kids* services are free to Medicaid enrolled children. Through the EPSDT program, the Title V Child Health agencies and their subcontractors implement care coordination services, which place a high priority on helping families make health care decisions for their child.

The care coordinator:

- Helps families make informed health care choices for their children
- Establishes and maintains medical homes and dental homes
- Reminds families that periodic well-child screenings and dental exams are due
- Assists with scheduling appointments
- Arranges support services such as transportation to providers, child care, or interpreter services
- Links families to health-related community services

Title V care coordinators provide services for Medicaid eligible or uninsured children. To access the EPSDT *Care for Kids* program coordinator for your county, you may call the Healthy Families Line at 1-800-369-2229 or use the map found on page 9.

***1st Five Healthy Mental Development Initiative:***

Several Title V child health agencies are also *1st Five* sites. Iowa's *1st Five* Healthy Mental Development Initiative builds partnerships between primary care provider practices and public service providers to enhance high quality well-child care. *1st Five* promotes the use of standardized developmental surveillance and screening tools in primary care provider practices that support healthy mental development for young children during their first five years. *1st Five* provides enhanced care coordination in the following way:

1. If a primary care provider has identified a concern, the provider will refer the family, upon receiving their consent, to the local *1st Five* health agency care coordinator.
2. The care coordinator will then link the family and child to the appropriate support and intervention services.
3. The care coordinator will monitor the progress of these services and update the provider on the status of the referral.

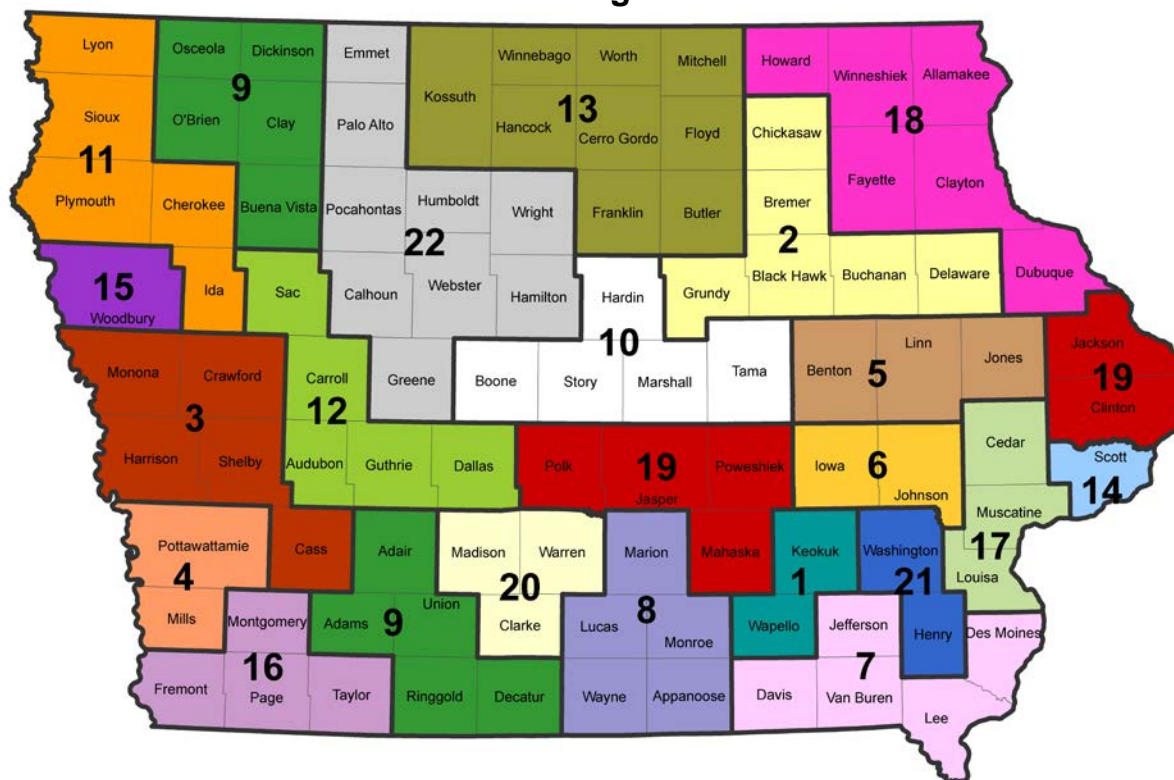
***1st Five care coordination is available to all children, regardless of insurance.*** To contact *1st Five*, you may call the state coordinator at 1-800-383-3826 or see page 11 for your *1st Five* site coordinator's contact information.

*Typical support and intervention services that 1st Five/Title V care coordinators refer to:*

Early ACCESS	Child Health Specialty Clinics	DHS resources
Area Education Agency	Adult education resources	Housing assistance
Stork's Nest programs	Vision/hearing screenings	Infant/child supplies
Parent support programs	Dental services	Lead testing
Food assistance programs	Mental health services	Maternal depression support
Head Start	Case management services	Home visit programs (PAT, HOPES)
Employment assistance	Substance abuse treatment	Abuse prevention services
Energy assistance	Transportation assistance	Other local services
Health insurance	Child care resources	

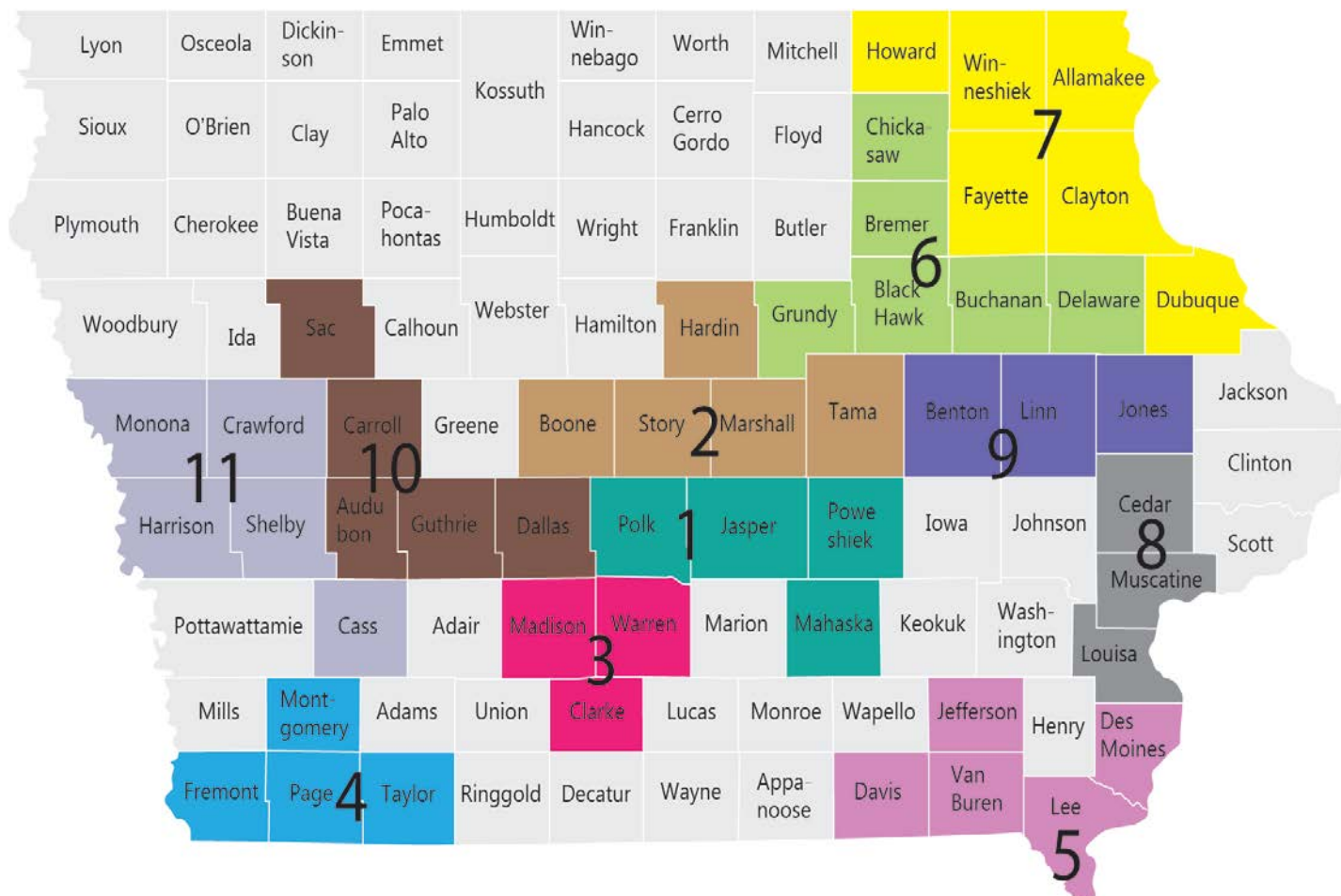


## EPSDT Care for Kids Program Coordinators



<b>1. American Home Finding Association</b> 333 Church Street Ottumwa, IA 52501 Denise Janssen (641) 682-8784 (800) 452-1098	<b>9. MATURA Action Corporation</b> 203 West Adams Street Creston, IA 50801 Mary Groves (641) 782-8431	<b>16. Taylor County Public Health</b> 405 Jefferson Street Bedford, IA 50833 Julie Thomas (712) 523-3405 (800) 425-0051
<b>2. Black Hawk County Health Department</b> 1407 Independence Avenue, 5th Floor Waterloo, IA 50703 Arlene Prather-O'Kane (319) 291-2413	<b>10. Mid-Iowa Community Action, Inc.</b> 1001 South 18th Avenue Marshalltown, IA 50158 Leah Fonua (641) 752-7162 Ext. 143	<b>17. Trinity Muscatine Public Health</b> 1609 Cedar Street Muscatine, IA 52761 Rebecca Schultz (563) 263-0122
<b>3. Crawford County Home Health, Hospice, &amp; PH</b> 105 North Main Street Denison, IA 51442 Gayle Chapman (712) 263-3303	<b>11. Mid-Sioux Opportunity, Inc.</b> 418 South Marion Street Remsen, IA 51050 Brittany Goodchild (712) 786-3418 (800) 859-2025	<b>18. Visiting Nurse Association of Dubuque</b> 1454 Iowa Street, P.O. Box 359 Dubuque, IA 52004 Stacey Killian (563) 556-6200 (800) 862-6133
<b>4. Family Inc.</b> 3501 Harry Langdon Blvd. Suite 150 Council Bluffs, IA 51503 Sarah Zach (712) 256-9566	<b>12. New Opportunities, Inc.</b> 23751 Hwy 30, P.O. Box 427 Carroll, IA 51401 Beth Liechti (712) 792-9266 Ext. 217 642-6330 (800)	<b>19. Visiting Nurse Services of Iowa</b> 1111 9th Street, Suite 320 Des Moines, IA 50314 Terri Walker (515) 558-9955
<b>5. Hawkeye Area Community Action Program, Inc.</b> 1515 Hawkeye Drive Hiawatha, IA 52233 Gloria Witzberger (319) 739-1531 (800) 332-5289	<b>13. North Iowa Community Action Organization</b> 100 1st Street NW; Suite 200 Mason City, IA 50401 Lisa Koppin (641) 423-5044 Ext. 17 (800) 657-5856	<b>20. Warren County Health Services</b> 301 North Buxton; Suite 203 Indianola, IA 50125 Andrea Jimmerson (515) 961-1074
<b>6. Johnson County Public Health</b> 855 South Dubuque Street, Suite 217 Iowa City, IA 52240 Erica Wagner (319) 356-6040 ext. 5891	<b>14. Scott County Health Department</b> 600 West 4th Street, 4th Floor Davenport, IA 52801 JaNan Less (563) 326-8618 ext. 8857	<b>21. Washington County Public Health &amp; Home Care</b> 110 North Iowa Avenue, Suite 300 Washington, IA 52353 Jen Weidman (319) 653-7758 (800) 655-7758
<b>7. Lee County Health Department</b> 2218 Avenue H Ft. Madison, IA 52627 Melissa Calvillo (319) 372-5225 (800) 458-6672	<b>15. Siouxland Community Health Center</b> 1021 Nebraska Street Sioux City, IA 51102 Lynnsey Davison (712) 202-1033 (888) 371-1965	<b>22. Webster County Health Department</b> 330 1st Avenue North, Suite L-2 Fort Dodge, IA 50501 Tricia Nichols (515) 573-4107 (888) 289-3318
<b>8. Marion County Public Health</b> 2003 North Lincoln P.O. Box 152 Knoxville, IA 50138 Rachel Cecil (641) 828-2238 Ext. 241		

# 1<sup>st</sup> Five Participating Implementation and Community Planning Counties, FY '14



## Implementation Sites

1. Visiting Nurse Services of Iowa
2. Mid-Iowa Community Action, Inc.
3. Warren County Health Services
4. Taylor County Public Health
5. Lee County Health Department
6. Black Hawk County Health Department
7. Visiting Nurse Association of Dubuque County

## Community Planning Sites

8. Trinity Muscatine Public Health
9. Hawkeye Area Community Action Program (HACAP)
10. New Opportunities, Inc.
11. HCCMS Family Health Services

<b>Implementation Counties</b>	<b>1<sup>st</sup> Five Agency Represented</b>	<b>Local Agency Contact</b>
Dallas, Jasper, Mahaska, Polk, Poweshiek	Visiting Nurse Services of Iowa 1200 University, Suite 205 Des Moines, IA 50314	Sarah Black Phone: 515.558.9608 Fax: 515.280.7623 Email: <a href="mailto:sarahb@vnsdm.org">sarahb@vnsdm.org</a>
Boone, Hardin, Marshall, Story, Tama	Mid-Iowa Community Action, Inc. 226 SE 16 <sup>th</sup> Street Ames, IA 50010	Amy Robak Phone: 515.956.3312 ext. 115 Fax: 515.956.3310 Email: <a href="mailto:amy.robak@micaonline.org">amy.robak@micaonline.org</a>
Clarke, Madison, Warren	Warren County Health Services 301 N. Buxton, Suite 203 Indianola, IA 50125	Jodene DeVault Phone: 515.961.1074 Fax: 515.961.1083 Email: <a href="mailto:wchs@co.warren.ia.us">wchs@co.warren.ia.us</a>
Fremont, Montgomery, Page, Taylor	Taylor County Public Health 405 Jefferson Street Bedford, IA 50833	Amy Doiel Phone: 712.523.3405 Fax: 712.427.0085 Email: <a href="mailto:1stFive@taylorcountyhealth.com">1stFive@taylorcountyhealth.com</a>
Davis, Des Moines, Jefferson, Lee, Van Buren	Lee County Health Department 2218 Ave H Fort Madison, IA 52627	Michele Ross Phone: 319.372.5225 Fax: 319.372.4374 Email: <a href="mailto:mross@leecountyhd.org">mross@leecountyhd.org</a>
Chickasaw, Black Hawk, Bremer, Buchanan, Delaware, Grundy	Black Hawk County Health Department 1407 Independence Ave. Room 446 Waterloo, IA 50703	Teresa King Phone: 319.292.2213 Fax: 319.291.2695 Email: <a href="mailto:tking@co.black-hawk.ia.us">tking@co.black-hawk.ia.us</a>
Allamakee, Clayton, Fayette, Dubuque, Howard, Winneshiek	Visiting Nurse Association of Dubuque County 1454 Iowa Street; PO Box 359 Dubuque, IA 52001	Brittany Hubanks Phone: NA Fax: NA Email: <a href="mailto:brittany.hubanks@unitypoint.org">brittany.hubanks@unitypoint.org</a>
<b>Community Planning Counties</b>	<b>1<sup>st</sup> Five Agency Represented</b>	<b>Local Agency Contact</b>
Cedar, Louisa, Muscatine	Trinity Muscatine Public Health 1609 Cedar Street Muscatine, IA 52761	Christy Roby Williams Phone: 563.262.2022 Fax: 563.263.0520 Email: <a href="mailto:christy.robbywilliams@unitypoint.org">christy.robbywilliams@unitypoint.org</a>
Benton, Jones, Linn	Hawkeye Area Community Action Program 1515 Hawkeye Drive Hiawatha, IA 52233	Kim Ott Phone: 319.393.7811 Fax: 319.6263 Email: <a href="mailto:kott@hacap.org">kott@hacap.org</a>
Audubon, Carroll, Dallas, Guthrie, Sac	New Opportunities, Inc. 23751 Hwy 30; PO Box 427 Carroll, IA 51401	Paula Klocke Phone: 712.792.9266 x201 Fax: 712.792.5723 Email: <a href="mailto:pklocke@newopp.org">pklocke@newopp.org</a>
Cass, Crawford, Harrison, Monona, Shelby	HCCMS Family Health Services 105 N. Main Street Denison, IA 51442	Kim Finernan Phone: 712.263.3303 Fax: 712.263.4033 Email: <a href="mailto:hccmsdirector@frontier.net">hccmsdirector@frontier.net</a>



## Iowa Recommendations for Scheduling Care for Kids Screenings

Revised 10/2009

KEY		AGE																							
		Infancy								Early Childhood				Late Childhood				Adolescence							
		2-3 <sup>1</sup> days	by 1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	2 yr	3 yr	4 yr	5 yr	6 yr	8 yr	10 yr	12 yr	14 yr	16 yr	18 yr	20+ yr			
History	Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
Physical exam	As part of each screening	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
Measurements	Length/height & weight	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
	Head circumference	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
	Body Mass Index										●	●	●	●	●	●	●	●	●	●	●	●			
	Blood pressure	risk assessment										●	●	●	●	●	●	●	●	●	●	●			
Nutrition	Assess/educate	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
Oral Health	Assessment - Dental history; recent concerns, pain or injury; visual inspection of hard and soft tissues of oral cavity; dental referral based on risk assessment	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
Development and behavioral assessment	Developmental screening <sup>2</sup>						●		●	●															
	Autism screening <sup>3</sup>								●	●															
	Developmental surveillance <sup>2</sup>	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
	Psychosocial/behavioral assessment	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
	Alcohol and drug use assessment	risk assessment to be performed with appropriate action to follow if positive →																●	●	●	●	●			
Sensory screening	Vision	S	S	S	S	S	S	S	S	S	S	○	○	○	○	S	○	○	S	○	○	○			
	Hearing	○	S	S	S	S	S	S	S	S	S	S	○	○	S	○	S	○	S	S	○	S			
Immunization	Perform an immunization review at each visit; administer immunizations at recommended ages, or as needed	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
Anticipatory Guidance	Provided at every visit	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			
PROCEDURES	Dyslipidemia										*	*			*	*	*	*	*	*	●	●			
	Hemoglobin/hematocrit	Perform once between 9-month and 12-month visits for children at risk; also annually for adolescents if risk factors are present																		●					
	Gynecologic testing	Screen for cervical dysplasia as part of a pelvic exam within 3 years of onset of sexual activity or age 21, whichever comes first. Pregnancy testing done as indicated.															*	*	*	*	*	●			
	Lead screening	Assess and test all children at 12 months and 2 years of age. In addition, assess and test high-risk children at 18 months, 3 years, 4 years and 5 years <sup>4</sup>								●	*	●	*	*	*										
	Metabolic screening	The Iowa Neonatal Metabolic Screening Program tests every newborn for all disorders on the American College of Medical Genetics and March of Dimes screening panels. See <a href="http://www.idph.state.ia.us/genetics">www.idph.state.ia.us/genetics</a> .								Ⓢ															
	Sexually transmitted infections	Screen as appropriate. People with a history of, or at risk for STIs should be tested for chlamydia and gonorrhea																		as appropriate					
	Tuberculin test	For high risk groups, annual testing is recommended. High risk groups include household members of persons with TB or others at risk for close contact with the disease; recent immigrants or refugees from countries where TB is common; migrant workers; residents of correctional institutions or homeless shelters; persons with certain underlying disorders								annual testing for high risk groups															

<sup>1</sup>For newborns discharged within 24 hours or less after delivery. <sup>2</sup>AAP Council on Children with Disabilities, AAP Section on Developmental Behavioral Pediatrics, AAP Bright Futures Steering Committee, AAP Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*, 2006;118:405-420.

<sup>3</sup>Gupta VB, Hyman SL, Johnson CP, et al. Identifying children with autism early? *Pediatrics*. 2007;119:152-153.

<sup>4</sup>For additional information, call the Bureau of Lead Poisoning Prevention at 1-800-972-2026.

## **Iowa Recommendations for Scheduling *Care for Kids* Screenings Development and Behavioral Assessment for Title V Child Health Agencies**

Iowa Recommendations for Scheduling *Care for Kids* Screenings (EPSDT Periodicity Schedule) was revised in July 2009 to better align with *Bright Futures* Third Edition, the American Academy of Pediatrics Guidelines for Health Supervision of Infants, Children, and Adolescents. The revised schedule includes delineation of the development and behavioral assessment section into five categories: developmental surveillance, developmental screening, psychosocial/behavioral assessment, autism screening, and alcohol and drug use assessment. This document is designed to provide Title V Child Health agencies with a brief summary for each category in the 'development and behavioral assessment' section of Iowa's Periodicity Schedule.

For more detailed information about developmental and behavioral surveillance and screening tools, see the Iowa EPSDT *Care for Kids* Provider Website at [www.iowaepsdt.org](http://www.iowaepsdt.org). A chart of screening tools found on this website is attached. Helpful information is also provided in the Medicaid Screening Center Provider Manual at [http://www.dhs.state.ia.us/policyanalysis/PolicyManualPages/Manual\\_Documents/Provman/scenter.pdf](http://www.dhs.state.ia.us/policyanalysis/PolicyManualPages/Manual_Documents/Provman/scenter.pdf) under Developmental Screening and Mental Health Assessment.

### **1. Developmental surveillance:**

- For agencies completing the full well child exam: Developmental surveillance is a component of the full well child exam. If you are using the **Iowa Child Health and Developmental Record (CHDR)** forms, these questions would be found in the 'Developmental' section. There is no separate billing for this service, as it would be included as part of the physical exam. (See <http://www.iowaepsdt.org/ScreeningResources/CHDR.htm> for the Iowa CHDR forms.)
- For agencies referring to a medical home for the well child exam: Completion of the **CHDR's** 'Developmental', 'Social History', and 'Anticipatory Guidance' sections have been approved for billing as a care coordination service. Documentation for the care coordination service must report use of the **CHDR** and reflect the scope of the service, findings from the family, and any referrals that may result.

### **2. Developmental screening:**

- In Iowa, there are several tools that are recommended. Our Title V Child Health programs were offered training on the **Ages and Stages Questionnaire (ASQ)** and **Ages and Stages S-E (ASQ SE)**. There are other developmental screening tools listed at [www.iowaepsdt.org](http://www.iowaepsdt.org) such as **Bayley Infant Neurodevelopment Screener**, **Brigance Infant and Toddler Screen**, and **Parents' Evaluation of Developmental Status (PEDS)**.
- The developmental screen may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

### **3. Autism screening:**

- In Iowa, there are two recommended tools, the **Modified Checklist for Autism in Toddlers (M-CHAT)** and the **Pervasive Development Disorders Screening Test II (PDDST II)**. (See [www.iowaepsdt.org](http://www.iowaepsdt.org).)
- The autism screen may be billed to Medicaid by Title V Child Health agencies using Code 96110. (Note that this code can only be billed once per visit (so at 18 months when both the developmental screen and autism screen are due, you could only bill one 96110 for the screenings provided). The autism screen is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

### **4. Psychosocial/behavioral assessment:**

- **Psychosocial/behavioral surveillance**
  - For agencies completing the full well child exam, psychosocial/behavioral surveillance is provided at each visit as a component of the full well child exam. If you are using the Iowa **Child Health and Developmental Record (CHDR)** forms, these questions would be found in the 'Social History' section. There is no separate billing for this service, as it would be included as part of the physical exam. (See <http://www.iowaepsdt.org/ScreeningResources/CHDR.htm> for the Iowa CHDR forms.)

- For agencies referring to a medical home for the well child exam: Completion of the **CHDR's** 'Developmental', 'Social History', and 'Anticipatory Guidance' sections have been approved for billing as a care coordination service. Documentation for the care coordination service must report use of the **CHDR** and reflect the scope of the service, findings from the family, and any referrals that may result.
- **Psychosocial/behavioral screening**
  - Psychosocial/behavioral screening may be provided using the **Pediatric Symptom Checklist** (See [http://www.brightfutures.org/mentalhealth/pdf/professionals/ped\\_symptom\\_chklst.pdf](http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_symptom_chklst.pdf).) There are two versions, a parent report and a youth self report (Y-PSC) for adolescents ages 11 – 18. The **Pediatric Symptom Checklist, Youth Self-Report (Y-PSC)** may be used to provide a mental health screen for 11-18 year old patients during well visits, sports physicals and other routine office visits.

Psychosocial/behavioral screening may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

## 5. Alcohol & drug use assessment:

- *Bright Futures* recommends the **CRAFFT Screening Tool**. The **CRAFFT** is a behavioral health screening tool for use with children under the age of 21 and is recommended by the American Academy of Pediatrics' Committee on Substance Abuse for use with adolescents. It consists of a series of 6 questions developed to screen adolescents for high risk alcohol and other drug use disorders simultaneously. It is a short, effective screening tool meant to assess whether a longer conversation about the context of use, frequency, and other risks and consequences of alcohol and other drug use is warranted. (See <http://www.ceasar-boston.org/CRAFFT/index.php>).

Use of the **CRAFFT Screening Tool** may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.



## Pediatric Symptom Checklist

### INSTRUCTIONS FOR SCORING

The Pediatric Symptom Checklist is a psychosocial screen designed to facilitate the recognition of cognitive, emotional, and behavioral problems so that appropriate interventions can be initiated as early as possible. Included here are two versions, the parent-completed version (PSC) and the youth self-report (Y-PSC). The Y-PSC can be administered to adolescents ages 11 and up.

The PSC consists of 35 items that are rated as "Never," "Sometimes," or "Often" present and scored 0, 1, and 2, respectively. The total score is calculated by adding together the score for each of the 35 items. For children and adolescents ages 6 through 16, a cutoff score of 28 or higher indicates psychological impairment. For children ages 4 and 5, the PSC cutoff score is 24 or higher (Little et al., 1994; Pagano et al., 1996). The cutoff score for the Y-PSC is 30 or higher. Items that are left blank are simply ignored (i.e., score equals 0). If four or more items are left blank, the questionnaire is considered invalid.

### HOW TO INTERPRET THE PSC OR Y-PSC

A positive score on the PSC or Y-PSC suggests the need for further evaluation by a qualified health (e.g., M.D., R.N.) or mental health (e.g., Ph.D., L.I.C.S.W.) professional. Both false positives and false negatives occur, and only an experienced health professional should interpret a positive PSC or Y-PSC score as anything other than a suggestion that further evaluation may be helpful. Data from past studies using the PSC and Y-PSC indicate that two out of three children and adolescents who screen positive on the PSC or Y-PSC will be correctly identified as having moderate to serious impairment in psychosocial functioning. The one child or adolescent "incorrectly" identified usually has at least mild impairment, although a small percentage of children and adolescents turn out to have very little or no impairment (e.g., an adequately functioning child or adolescent of an overly anxious parent). Data on PSC and Y-PSC negative screens indicate 95 percent accuracy, which, although statistically adequate, still means that 1 out of 20 children and adolescents rated as functioning adequately may actually be impaired. The inevitability of both false-positive and false-negative screens underscores the importance of experienced clinical judgment in interpreting PSC scores. Therefore, it is especially important for parents or other laypeople who administer the form to consult with a licensed professional if their child receives a PSC or Y-PSC positive score.

For more information, visit the Web site: <http://psc.partners.org>.

### REFERENCES

- Jellinek MS, Murphy JM, Little M, et al. 1999. Use of the Pediatric Symptom Checklist (PSC) to screen for psychosocial problems in pediatric primary care: A national feasibility study. *Archives of Pediatric and Adolescent Medicine* 153(3):254-260.
- Jellinek MS, Murphy JM, Robinson J, et al. 1988. Pediatric Symptom Checklist: Screening school-age children for psychosocial dysfunction. *Journal of Pediatrics* 112(2):201-209. Web site: <http://psc.partners.org>.
- Little M, Murphy JM, Jellinek MS, et al. 1994. Screening 4- and 5-year-old children for psychosocial dysfunction: A preliminary study with the Pediatric Symptom Checklist. *Journal of Developmental and Behavioral Pediatrics* 15:191-197.
- Pagano M, Murphy JM, Pedersen M, et al. 1996. Screening for psychosocial problems in 4-5 year olds during routine EPSDT examinations: Validity and reliability in a Mexican-American sample. *Clinical Pediatrics* 35(3):139-146.

# Pediatric Symptom Checklist—Youth Report (Y-PSC)

Please mark under the heading that best fits you:

		Never	Sometimes	Often
1. Complain of aches or pains	1			
2. Spend more time alone	2			
3. Tire easily, little energy	3			
4. Fidgety, unable to sit still	4			
5. Have trouble with teacher	5			
6. Less interested in school	6			
7. Act as if driven by motor	7			
8. Daydream too much	8			
9. Distract easily	9			
10. Are afraid of new situations	10			
11. Feel sad, unhappy	11			
12. Are irritable, angry	12			
13. Feel hopeless	13			
14. Have trouble concentrating	14			
15. Less interested in friends	15			
16. Fight with other children	16			
17. Absent from school	17			
18. School grades dropping	18			
19. Down on yourself	19			
20. Visit doctor with doctor finding nothing wrong	20			
21. Have trouble sleeping	21			
22. Worry a lot	22			
23. Want to be with parent more than before	23			
24. Feel that you are bad	24			
25. Take unnecessary risks	25			
26. Get hurt frequently	26			
27. Seem to be having less fun	27			
28. Act younger than children your age	28			
29. Do not listen to rules	29			
30. Do not show feelings	30			
31. Do not understand other people's feelings	31			
32. Tease others	32			
33. Blame others for your troubles	33			
34. Take things that do not belong to you	34			
35. Refuse to share	35			



# Pediatric Symptom Checklist—Youth Report (Y-PSC)

Please mark under the heading that best fits you:

		Never	Sometimes	Often
1. Complain of aches or pains	1			
2. Spend more time alone	2			
3. Tire easily, little energy	3			
4. Fidgety, unable to sit still	4			
5. Have trouble with teacher	5			
6. Less interested in school	6			
7. Act as if driven by motor	7			
8. Daydream too much	8			
9. Distract easily	9			
10. Are afraid of new situations	10			
11. Feel sad, unhappy	11			
12. Are irritable, angry	12			
13. Feel hopeless	13			
14. Have trouble concentrating	14			
15. Less interested in friends	15			
16. Fight with other children	16			
17. Absent from school	17			
18. School grades dropping	18			
19. Down on yourself	19			
20. Visit doctor with doctor finding nothing wrong	20			
21. Have trouble sleeping	21			
22. Worry a lot	22			
23. Want to be with parent more than before	23			
24. Feel that you are bad	24			
25. Take unnecessary risks	25			
26. Get hurt frequently	26			
27. Seem to be having less fun	27			
28. Act younger than children your age	28			
29. Do not listen to rules	29			
30. Do not show feelings	30			
31. Do not understand other people's feelings	31			
32. Tease others	32			
33. Blame others for your troubles	33			
34. Take things that do not belong to you	34			
35. Refuse to share	35			

Screening Tools	Age Range Covered	Areas Screened	Format	Who Can Complete It	Administration Time	Validity and Reliability	Scoring	Languages	Purchase/Obtainment Information
<b>Developmental Screening Tools</b>									
Ages and Stages Questionnaire (ASQ)	4-60 mo	communication, gross motor, fine motor, problem-solving, and personal-social	Series of 19 age-specific questionnaires	Parents	10-15 min	Normed on 2,008. Sensitivity (0.70-0.90: moderate to high) specificity (0.76-0.91- moderate to high)	Scored by professionals. results in pass/fail domain. Provides a cutoff score in 5 domains that indicate possible need for further evaluation	English, Spanish, French, Korean and Others	Paul H. Brookes Publishing Co: 800/638-3775; www.brookespublishing.com
Ages and Stages Questionnaire S-E (ASQ)	6-60 mo	Social-emotional (self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people)	Series of 8 age-specific questionnaires	Parents	10-15 min	Normed on 3,000. Very good validity and reliability	Scored by professionals.	English and Spanish	Paul H. Brookes Publishing Co: 800/638-3775; www.brookespublishing.com
Bayley Infant Neurodevelopment Screener	3-24 mo	neurologic functions, receptive functions (visual, auditory, and tactile input), expressive functions (oral, fine, and gross motor skills), and cognitive processes	Series of 6 item sets	Directly administered	10 min	Normed on ~1,700. Sensitivity (0.7-0.86: moderate) specificity (0.75-0.86- moderate)	Graded as low, moderate, or high risk in each of 4 conceptual domains by use of 2 cutoff scores	English and Spanish	Psychological Corp: 800/211-8378; www.harcourtassessment.com
Brief Infant-Toddler Social and Emotional Assessment (BITSEA)	12-36 mo	assess emerging social-emotional development	42 items	Directly administered	7-10 min	National sample of 600 children. Clinical groups included language delayed, premature, and other diagnosed disorders.	Problems total score and competence total score	English and Spanish	www.harcourtassessment.com
Brigance Infant and Toddler Screen	0-90 mo	articulation, expressive and receptive language, gross motor, fine motor, general knowledge, personal social skills, and academic skills (when appropriate)	Series of 9 forms	Directly administered	10-15 min	Normed on 1,156 children from 29 clinical sites in 21 states. Sensitivity (0.70-0.80: moderate) Specificity (0.70-0.80: moderate)	All results are criterion based. No normative data are presented.	English and Spanish	Curriculum Associates Inc. 800/225-0248; www.curriculumassociates.com
Child Development Review	18 mo- 5 yr	social, self-help, motor, and language	6 open-ended questions and a 26 item possible-problems checklist to be completed by the parent	Parent	10-20 min	Standardized with 220 children 3-4 yrs from primarily white, working class families in south St. Paul, MN; sensitivity (0.68: low) specificity (0.88: moderate)	Responses are classified as indicating: (1) no problem, (2) a possible problem, or (3) a possible major problem	English and Spanish	Behavior Science Systems Inc.

Screening Tools	Age Range Covered	Areas Screened	Format	Who Can Complete It	Administration Time	Validity and Reliability	Scoring	Languages	Purchase/Obtainment Information
<b>Developmental Screening Tools</b>									
Denver Developmental Screening Test (Denver II)**	0-6 yr	expressive and receptive language, gross motor, fine motor, and personal-social skills	125 items	Directly administered	10-20 min	Normed on 2,096 term children in Colorado. sensitivity (0.68: low) specificity (0.0.43-0.80: low to moderate)	pass/fail then compared with age-based norms to classify as normal, suspect or delayed	English and Spanish	Denver Developmental Materials: 800/419-4729; www.denverii.com
Infant Development Inventory	0-18 mo	social, self-help, motor, and language	4 open-ended questions followed by 87 items crossing the 5 domains	Parent	5-10 min	Studied in 86 high-risk 8 mo-olds seen in perinatal follow-up program and compared with Bayley scales. Sensitivity (0.85: moderate) specificity (0.77: moderate)	delayed or not delayed	English and Spanish	Behavior Science Systems Inc.
Parents' Evaluation of Developmental Status (PEDS)	0-8 yr	developmental and behavioral problems needing further evaluation (may be useful as a surveillance tool)	single response form used for all ages	Interview of parent	2-10 min	Standardized with 771 children from diverse ethnic and socioeconomic backgrounds. Sensitivity (0.74-0.79: moderate) specificity (0.70-0.80: moderate)	provides algorithm to guide need for referral, additional screening, or continued surveillance	English, Spanish, Vietnamese, Arabic, Swahili, Indonesian, Chinese, Taiwanese, French, Somali, Portuguese, Malaysian, Thai, and Laotian	Ellsworth & Vandermeer Press LLC: 888/729-1697; www.pedstest.com
** Recent studies have shown the specificity of the Denver II to be lower than some of the other tools currently on the market. The Denver II does not include the social/emotional criteria at the same level as the other screening tools.									
<b>Autism Screening Tools</b>									
Modified Checklist for Autism in Toddlers (M-CHAT)	16-48 mo	autism	23 questions (average)	Parent	5-10 min	Standardized sample included 1,293 children screened, 58 evaluated, and 39 diagnosed with an autistic spectrum disorder. Sensitivity (0.85-0.87: moderate) specificity (0.93-0.99: high)	risk categorization pass/fail	English, Spanish, Turkish, Chinese and Japanese	Public domain: www.firstsigns.com
Pervasive Developmental Disorders Screening Test II (PDDST II)	12-48 mo	autism	22 questions (average)	Parent	10-15 min	Validated using extensive multi-method diagnostic evaluations on 681 children at risk of autistic spectrum disorders and 256 children with mild-to-moderate other developmental disorders. Sensitivity (0.85-0.92: moderate to high) specificity (0.71-0.91: moderate to high)	risk categorization pass/fail	English	Psychological Corp

Screening Tools	Age Range Covered	Areas Screened	Format	Who Can Complete It	Administration Time	Validity and Reliability	Scoring	Languages	Purchase/Obtainment Information
<b>Parent/Caregiver Screening Tools</b>									
Edinburgh Postnatal Depression Scale (EPDS)	mothers	postnatal depression	ten item scale	Self-administered	5 min	sensitivity (0.86) specificity (0.78)	max score of 30, score of 10+ may indicate depression	many languages	UIC Perinatal Consultation: 800/573-6121
Parenting Stress Index Short Form	parents of children 1 mo-12 yr	Identify parent-child problem areas in parents	36 items	Self-administered	10 min	reliability (0.78-0.90) validity (0.50-0.92)	Total Stress score from three scales: parental distress, parent-child dysfunctional interaction, and difficult child.	many languages	www3.parinc.com
Pediatric Intake Form (PIF) from Bright Futures	parent/ family history	parental depression, substance use, domestic violence, history of abuse, social supports, and other risk factors	66 questions (average)	Self-administered	10-20 min	no data	A score of 4 or more risk factors indicates child should be referred for early stimulation programs	no data	www.brightfutures.org
<b>Psychosocial/behavioral Screening Tools</b>									
Pediatric Symptom Checklist	4 - 18 yr	problem behaviors including both externalizing (conduct, attention, etc.) and internalizing (depression, anxiety, adjustment, etc.)	35 short statements	Parents	10 min	no data	Ratings of never, sometimes or often are assigned a value of 0,1,or 2. Scores totaling 28 or more suggest referrals. For children 4 - 5 years of age, several items referring to academic performance are omitted and a cutoff of 24 is used.	Spanish and Chinese	<a href="http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_sympton_chklist.pdf">http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_sympton_chklist.pdf</a>
Pediatric Symptom Checklist, Youth Self-Report	adolescent ages 11 -18	problem behaviors including both externalizing (conduct, attention, etc.) and internalizing (depression, anxiety, adjustment, etc.)	35 short statements; 37 with 2 suicide screening questions	Self-administered	10 min	no data	Ratings of never, sometimes or often are assigned a value of 0,1,or 2. Scores totaling 28 or more suggest referrals. (30 or more with the 2 suicide screening questions)	Spanish and Chinese	<a href="http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_sympton_chklist.pdf">http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_sympton_chklist.pdf</a>
<b>Alcohol and Drug Use Screening Tool</b>									
CRAFT	adolescents under age 21	screens for high risk alcohol and other drug use disorders	3 questions followed by 6 additional questions depending upon response	Provider or self-administered	5 min	no data	Determines whether a longer conversation about the context of use, frequency, and other risks and consequences of alcohol and other drug use is warranted.	English, Spanish, and Portuguese	Recommended by AAP <a href="http://www.brightfutures.org">www.brightfutures.org</a> <a href="http://www.ceasar-boston.org/CRAFT/index.php">http://www.ceasar-boston.org/CRAFT/index.php</a>

- **Developmental surveillance is included as part of a regular well-child exam.**

Well-child exams should include all of the following:

- Comprehensive health, nutrition, and developmental history
- Review of physical, mental health, and developmental status
- Review of family risk factors, including family stress and maternal depression
- Unclothed physical exam
- Immunization history
- Oral health screening
- Counseling, anticipatory guidance, risk factor reduction interventions
- Ordering appropriate immunizations or laboratory/diagnostic procedures

Well-child visits can be billed under the following codes:

Age range	New patients	Established patients
Less than 1 year	99381	99391
1-4 years	99382	99392
5-11 years	99383	99393
12-17 years	99384	99394
18-21 years	99385	99395

- **Developmental screening can be billed as a separate service on the same day:**

**Limited developmental testing** with interpretation and report. *Developmental screening and social emotional screening that includes use of a limited screening instrument may be billed in addition to the preventive medicine services, or with other evaluation and management services. In order for the test to be billed as a separate service the interpretation and report must be a significant, distinct service. Bill under code 96110. As of June 2010, the maximum rate for reimbursement is \$64.12. 96110 can only be billed once for the same day and same patient.*

Medicaid and *hawk-i* policies reimburse for developmental screenings under code 96110, as do **many private insurance policies**, including the majority of Wellmark and UnitedHealthCare plans.

- **Submitting Medicaid Claims:**

*Electronic:* Submitting claims electronically will result in faster reimbursement. Iowa Medicaid Enterprise (IME) offers free software for submitting electronic claims. Contact the Electronic Data Interchange Support Services (EDISS) coordinator at 1-800-967-7902. Or visit the IME web site at [www.ime.state.ia.us](http://www.ime.state.ia.us).

- **Steps to reimbursement:**

1. **Verify eligibility** by visiting the web portal or by calling the Eligibility Verification System (ELVS) at 800-338-7752 or 515-323-9639.
  - Eligibility can be verified using Medicaid ID number or social security number and birth date.
  - To establish a web portal account, call 800-967-7902.
2. **Include required information**
  - Member's Medicaid number
  - Member's first and last names and middle initial
  - Date and place of service
  - Provider NPI number



# STATE OF IOWA

CHESTER J. CULVER, GOVERNOR  
PATTY JUDGE, LT. GOVERNOR

DEPARTMENT OF HUMAN SERVICES  
KEVIN W. CONCANNON, DIRECTOR

## Informational Letter No. 590

March 16, 2007

**To:** Physicians, Nurse Practitioners  
**From:** Iowa Department of Human Services, Iowa Medicaid Enterprise  
**Re:** Billing Developmental Services

Developmental surveillance and screening during preventive health care visits allows the primary care provider an opportunity to offer anticipatory guidance to the family about supporting their child's development, facilitate early intervention and treatment, and improve developmental outcomes. Payment for conducting developmental screening using a standardized screening tool or conducting an in-depth developmental evaluation is not included in the reimbursement for a child's preventive office visit or E/M service. When a standardized screening or evaluation is performed, providers should bill using the following codes:

**96110 Developmental testing; limited (e.g., Developmental Screening Test II, Early Language Milestone Screen), with interpretation and report**

The use of developmental and social-emotional screening instruments of a limited nature (e.g., PEDS, Ages and Stages, Brief Infant-Toddler Social Emotional Assessment--BITSEA, Modified Checklist for Autism in Toddlers--M-CHAT and Vanderbilt ADHD rating scales) is reported using CPT code 96110 (*developmental testing; limited*). Code 96110 is often reported when performed in the context of preventive medicine services, but may also be reported when testing is performed with other evaluation and management (E/M) services such as acute illness or follow-up office visits.

**96111 Developmental testing; extended (includes assessment of motor, language, social, adaptive and/or cognitive functioning by standardized developmental instruments) with interpretation and report**

Extended developmental evaluation using standardized instruments (e.g., Bayley Scales of Infant Development, Woodcock-Johnson Tests of Cognitive Abilities (Third Edition) and Clinical Evaluation of Language Fundamentals (Fourth Edition)) is reported using CPT code 96111. This service may be reported independently or in conjunction with another code describing a separate patient encounter provided on the same day as the testing (e.g., an evaluation and management code for outpatient consultation). When 96111 is reported in conjunction with an E/M service, the time and effort to perform the developmental testing itself should not count toward the key components (history, physical exam, and medical decision making) or time for selecting the accompanying E/M code.

The Iowa Medicaid program encourages providing surveillance and screening of a child's development on a regular basis. Additional information and a "short list" of domain-specific screening tools recommended by a Panel of Iowa health care providers can be found at [www.iowaepsdt.org](http://www.iowaepsdt.org). To view the recently released screening policy from the American Academy of Pediatrics go to <http://pediatrics.aappublications.org/cgi/content/full/118/1/405>.

**Name of Child** \_\_\_\_\_

**Lives with:**    ↑ 1 parent    ↑ 2 parents    ↑ Other caregivers \_\_\_\_\_

↑ Other (include brothers, sisters, and other family, etc.) \_\_\_\_\_

### **DEVELOPMENTAL MILESTONES**

What new things is your baby doing?

### **Does your baby.... (Circle Yes or No)**

Smiles at the sound of your voice or when smiled at                      **Yes No**

Raises head when laying on tummy    **Yes No**

Responds to loud noises    **Yes No**

Follows moving objects with his/her eyes                                      **Yes No**

Makes sounds with his/her voice    **Yes No**

Concerns about development or behavior?                                      **Yes No**

(If yes, explain) \_\_\_\_\_

What other questions or concerns do you have today?

### **FAMILY HISTORY: Circle if present**

Depression or other mental illness, drug/alcohol abuse, learning problems, violence, heart disease, high blood pressure, diabetes, kidney disease, deafness, cancer, other (note): \_\_\_\_\_

### **SOCIAL HISTORY:**

How much stress are you and your family under now?

↑ None ↑ Slight ↑ Moderate ↑ Severe

What kind of stress?

↑ Relationships ↑ Drugs ↑ Alcohol ↑ Violence/Abuse ↑ Lack of help

↑ Financial ↑ Health Insurance ↑ Child Care ↑ Other \_\_\_\_\_

How stressful is caring for your child?

↑ None ↑ Slight ↑ Moderate ↑ Severe

In the past month, have you felt down, depressed or hopeless?

↑ No ↑ Sometimes ↑ Often

In the past month have you felt little interest or pleasure in doing things?

↑ No ↑ Sometimes ↑ Often

-----  
**Name of Your Medical Practice: Address**

**Phone: (xxx) xxx-xxxx**

**Fax: (xxx) xxx-xxxx**

**Nombre del niño(a)** \_\_\_\_\_

**Vive con:** †El papá †La mamá †En pareja †Otros (por ejemplo: una nana/niñera/guardián)

†Otros (incluya hermanos y hermanas y familiares, etc.)

## Etapas del Desarrollo

¿Que cosas nuevas estas haciendo su bebe?

## Su bebe... (Circule Si o No)

Sonríe al escuchar su voz o responde con sonrisas cuando alguien le sonríe **Si No**

Levanta la cabeza cuando esta boca bajo **Si No**

Responde a los ruidos fuertes **Si No**

Sigue un objeto con la mirada **Si No**

Hace ruidos con su voz / balbucea **Si No**

¿Tiene la familia preocupaciones sobre el desarrollo o comportamiento de el/la niño(a)? **Si No**  
(Si la respuesta es si, explique) \_\_\_\_\_

¿Que otras preguntas o preocupaciones tiene hoy?

## HISTORIA FAMILIAR: Ponga un círculo alrededor de los problemas que estén presentes en su familia

Depresión u otra enfermedad mental, abuso de drogas/alcohol, problemas de aprendizaje, violencia, enfermedades del corazón, hipertensión (presión alta), diabetes, enfermedad de los riñones, sordera, cáncer, otro (explique): \_\_\_\_\_

## HISTORIA SOCIAL:

¿Ahorita cuánto estrés tiene usted y su familia?

† Nada † Un poco † Moderado † Mucho

¿Qué clase de estrés?

† Relaciones † Drogas † Alcohol † Violencia/Abuso † Falta de ayuda † Económico

† Seguro médico † Guardería † Otro \_\_\_\_\_

¿Cuánto estrés le produce el cuidado de su niño(a)?

† Nada † Un poco † Moderado † Mucho

¿En el último mes se ha sentido triste, deprimida(o), o desesperada(o)?

† No † A veces † Seguido

¿En el último mes ha sentido poco interés o placer haciendo cosas?

† No † A veces † Seguido

Name of Your Medical Practice: Address

Phone: (xxx) xxx-xxxx

Fax: (xxx) xxx-xxxx





# [Child Health Agency]

1<sup>st</sup> Five Healthy Mental Development Initiative

## Referral Form

[Phone] [Fax Number]  
[Name]

Child's Name	Sex <b>M</b> <b>F</b>	DOB	Referral Date
circle one of the following: Uninsured <i>hawk-i</i> Private Insurance Medicaid			
Medical Provider	Telephone	Contact Person	
<b>Reason for referral to 1<sup>st</sup> Five:</b> <input type="checkbox"/> <i>Developmental Concerns</i> (Please fax copy of pink or yellow developmental screening sheet) <input type="checkbox"/> <i>Social Stressors</i> (Please fax copy of parental screening form) <input type="checkbox"/> <i>Dental Health</i> <input type="checkbox"/> <i>Other</i>			
Brief description of problem(s):		Identified needs of child/family for follow-up services:	
Screening Tool Used		Screening Date	
Parent or Caretaker's Name		Telephone	
Address	List any Communication Barriers		
<p align="center"><b>Release of Information</b></p> <p>I give _____ permission to contact [Child Health Agency] regarding potential services available through the 1<sup>st</sup> Five Project. I understand that information may be exchanged between the 1<sup>st</sup> Five Project, the medical provider, and any of the referral sources listed below.</p> <p>Signature _____ Relationship _____ Date _____</p>			
<b>Possible Referral Sources</b>	<b>The following programs apply as possible referral sources:</b>		
<b>Parent Education - Support Services</b>	PAT HOPES Stork's Nest Support Groups Other:		
<b>Early Intervention - Evaluation Services</b>	Early ACCESS AEA Child Specialty Clinics Other:		
<b>School Readiness Programs</b>	Developmental Preschool Early Head Start Head Start Programs Other:		
<b>Other Social Services</b>	Food Stamps/Food Pantries Clothing Assistance General Relief WIC		
	Housing Assistance Domestic Violence Nutrition Education DHS		
	Legal Aid Financial Assistance Employment Services <i>hawk-i</i>		
<b>Transportation</b>			
<b>Other Health Related Services</b>	Tobacco Cessation Immunizations Lead Testing Dental Other:		
<p><b>Note: If the information to be exchanged includes mental health treatment, substance abuse treatment, or HIV-related information, the authorization on the reverse side of this form must be completed prior to the exchange of information.</b></p>			

Referral Follow-up Update: (completed by care coordinator and faxed back to medical practice)



## Specific Authorization for Release of Information Protected by State or Federal Law Concerning Mental Health, Substance Abuse Treatment, or HIV/AIDS Related Information

I acknowledge that information to be exchanged may include information that is protected by state and/or federal law applicable to substance abuse, mental health, and/or HIV/AIDS related information. I SPECIFICALLY AUTHORIZE the exchange of the following confidential information between the [1<sup>st</sup> Five Project] or [Child Health Agency Name], the referring medical provider, and any of the referral sources listed on the front of this form: [place “yes” or “no” before each applicable category of information]

\_\_\_\_\_ Substance Abuse (drug or alcohol) information from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

\_\_\_\_\_ Mental Health information from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

\_\_\_\_\_ HIV or AIDS-related information, diagnosis, and test results from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

Furthermore, I SPECIFICALLY AUTHORIZE disclosure and re-disclosure of this confidential information to all of the persons referred to on the front of this form.

In order for the above information to be released or exchanged you must sign here and on the front of this form:

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Street Address

\_\_\_\_\_  
City/State/Zip

State or federal law specifically requires that any disclosure or re-disclosure of substance abuse, alcohol or drug, mental health, or HIV/AIDS-related information be accompanied by the following written statement:

This information has been disclosed to the persons referred to on the front of this form from records protected by federal confidentiality rules (42 CFR Part 2). The federal rules prohibit these individuals from making any further disclosure of this information unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR Part 2. A general authorization for the release of medical or other information is NOT sufficient for this purpose. The federal rules restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

See also Iowa Code Chapter 228 and Iowa Code section 141A.9 and other applicable laws.

## Plan-Do-Study-Act (PDSA) Planning Sheet

**Proposed team members:**

---

**Practice leader(s) needed to endorse changes for practice:**

---

### PLAN

**Objective for this cycle:**

---

**Potential barriers that may be encountered and how they will be addressed:**

Barrier 1:

---

Plan to reduce/eliminate Barrier 1:

---

Barrier 2:

---

Plan to reduce/eliminate Barrier 2:

---

**Plan for making the change:**

Who will do each part of the change?

What will each person do?

When will the change start?

Where will materials needed be located and retained?

**Plan for the collection of data to identify gaps in performance and the extent to which the change occurred:**

What data will be collected to set the baseline and check for change?

Who will collect the data?

When will it be collected?

How will the data be reported and shared?

Healthy mental development in the first five years



### 1st Five Potential Reasons for Referral

- ☐ Early Intervention & Evaluation Services
- ☐ Developmental Delay
- ☐ Speech Therapy
- ☐ Occupational Therapy
- ☐ Physical Therapy
- ☐ Financial Stress
- ☐ Family/Relationship Stress
- ☐ Domestic Abuse
- ☐ Child Care
- ☐ Head Start & Preschool
- ☐ Family Support Services
- ☐ Housing Resources
- ☐ Maternal/Caregiver Depression
- ☐ Mental Health Issues
- ☐ Behavior Issues
- ☐ Parent Education Programs
- ☐ Food Assistance
- ☐ Family Planning
- ☐ Medicaid/Dental/**hawk-i** Insurance Needs
- ☐ Substance Abuse
- ☐ Transportation Concerns

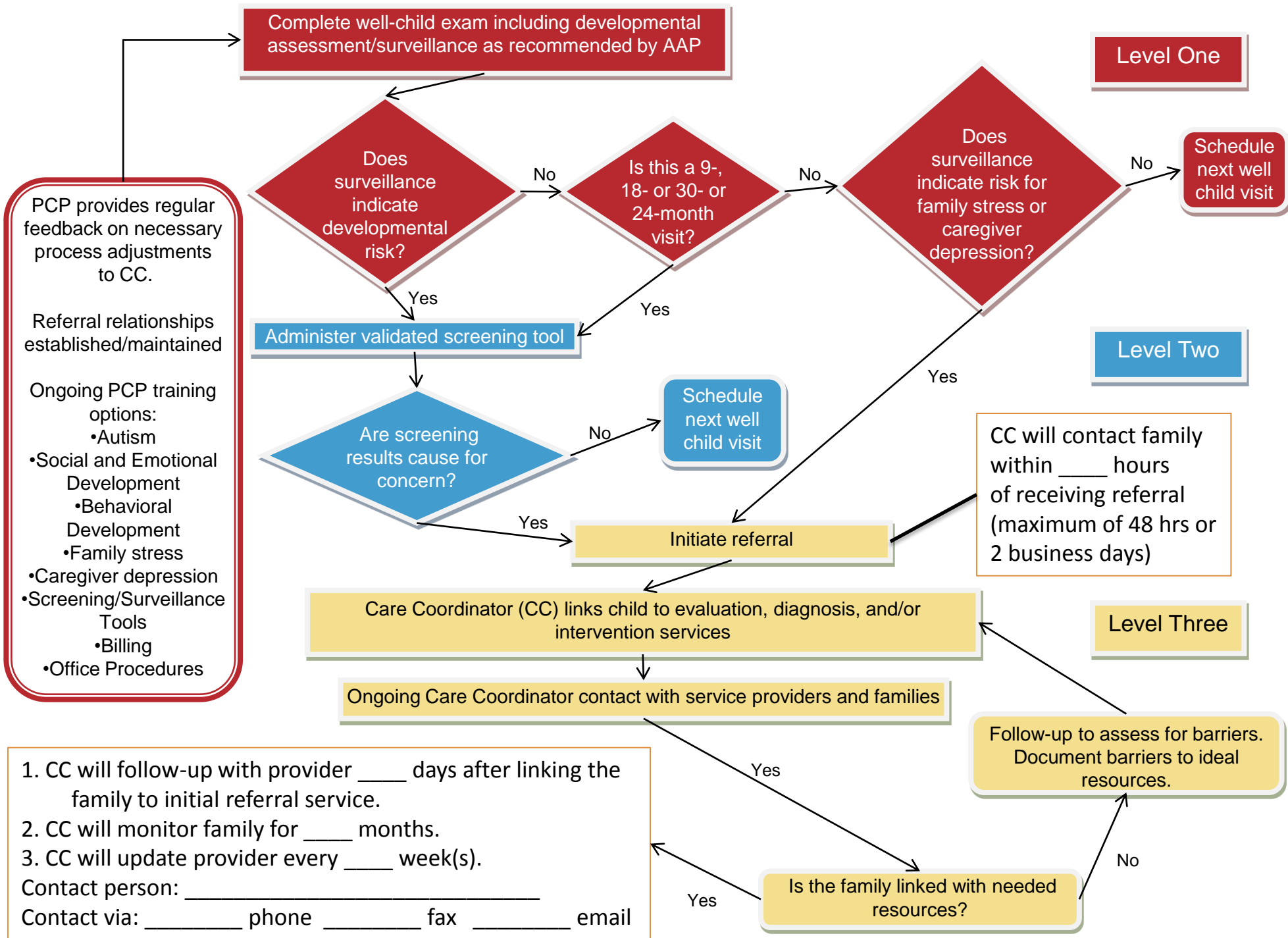
Healthy mental development in the first five years



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- ☐ Food Assistance
- ☐ Family Planning
- ☐ Medicaid/Dental/**hawk-i** Insurance Needs
- ☐ Substance Abuse
- ☐ Transportation Concerns

# PROTOCOL FOR PROVIDER:





**[Child Health Agency]**  
**1<sup>st</sup> Five Healthy Mental Development Initiative**  
**Referral Form**

**[Phone]** **[Fax Number]**

**[NAME]**

(If 1<sup>st</sup> Five site: 1<sup>st</sup> Five Project Coordinator, If not 1<sup>st</sup> Five site: EPSDT Coordinator)

Child's Name		Sex <b>M</b> <b>F</b>	DOB	Referral Date
circle one of the following:      Uninsured <b>hawk-i</b> Private Insurance      Medicaid				
Medical Provider		Telephone		Contact Person
<b>Reason for referral to 1<sup>st</sup> Five:</b> <input type="checkbox"/> <b>Developmental Concerns</b> (Please fax copy of pink or yellow developmental screening sheet) <input type="checkbox"/> <b>Social Stressors</b> (Please fax copy of parental screening form) <input type="checkbox"/> <b>Dental Health</b> <input type="checkbox"/> <b>Other</b>				
Brief description of problem(s):		Identified needs of child/family for follow-up services:		
Screening Tool Used			Screening Date	
Parent or Caretaker's Name			Telephone	
Address		List any Communication Barriers		
<b>Release of Information</b>				
I give _____ permission to contact <b>[Child Health Agency]</b> regarding potential services available through the 1 <sup>st</sup> Five Project. I understand that information may be exchanged between the 1 <sup>st</sup> Five Project, the medical provider, and any of the referral sources listed below.				
Signature _____ Relationship _____ Date _____				
<b>Possible Referral Sources</b>		<b>The following programs apply as possible referral sources:</b>		
Parent Education - Support Services	PAT    HOPES    Stork's Nest    Support Groups    Other:			
Early Intervention - Evaluation Services	Early ACCESS    AEA    Child Specialty Clinics    Other:			
School Readiness Programs	Developmental Preschool    Early Head Start    Head Start Programs    Other:			
Other Social Services	Food Stamps/Food Pantries		Clothing Assistance	General Relief    WIC
	Housing Assistance		Domestic Violence	Nutrition Education    DHS
	Legal Aid	Financial Assistance	Employment Services <b>hawk-i</b>	
Transportation				
Other Health Related Services	Tobacco Cessation    Immunizations    Lead Testing    Dental    Other:			
<b>Note: If the information to be exchanged includes mental health treatment, substance abuse treatment, or HIV-related information, the authorization on the reverse side of this form must be completed prior to the exchange of information.</b>				
<b>Referral Follow-up Update: (completed by care coordinator and faxed back to medical practice)</b>				

# Specific Authorization for Release of Information Protected by State or Federal Law Concerning Mental Health, Substance Abuse Treatment, or HIV/AIDS Related Information

I acknowledge that information to be exchanged may include information that is protected by state and/or federal law applicable to substance abuse, mental health, and/or HIV/AIDS related information. I SPECIFICALLY AUTHORIZE the exchange of the following confidential information between the [1<sup>st</sup> Five Project] or [Child Health Agency Name], the referring medical provider, and any of the referral sources listed on the front of this form: [place "yes" or "no" before each applicable category of information]

\_\_\_\_\_ Substance Abuse (drug or alcohol) information from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

\_\_\_\_\_ Mental Health information from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

\_\_\_\_\_ HIV or AIDS-related information, diagnosis, and test results from all health care providers, facilities, sources, and any other person or entity in possession of records concerning me.

Furthermore, I SPECIFICALLY AUTHORIZE disclosure and re-disclosure of this confidential information to all of the persons referred to on the front of this form.

In order for the above information to be released or exchanged you must sign here and on the front of this form:

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Street Address

\_\_\_\_\_  
City/State/Zip

State or federal law specifically requires that any disclosure or re-disclosure of substance abuse, alcohol or drug, mental health, or HIV/AIDS-related information be accompanied by the following written statement:

This information has been disclosed to the persons referred to on the front of this form from records protected by federal confidentiality rules (42 CFR Part 2). The federal rules prohibit these individuals from making any further disclosure of this information unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR Part 2. A general authorization for the release of medical or other information is NOT sufficient for this purpose. The federal rules restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

See also Iowa Code Chapter 228 and Iowa Code section 141A.9 and other applicable laws.

(Name of Title V/Child Health Agency)

Fax Back Referral Form

(xxx)xxx-xxxx Phone (xxx)xxx-xx xx Fax

Contact: xxxxxxxxxxxx

Nombre del Niño: _____		Sexo M F	Fecha de Nacimiento:	Fecha de Remisión:
circle one of the following: Uninsured <i>hawk-i</i> Private Insurance Medicaid				
Médico:		Teléfono:		Persona de contacto:
Razón por remisión a (Title V/Child Health Agency): <input type="checkbox"/> <i>Preocupaciones sobre desarrollo en el paciente</i> (Please fax copy of developmental screening sheet) <input type="checkbox"/> <i>Factores sociales de estrés</i> (Please fax copy of parental screening form) <input type="checkbox"/> <i>Salud Dental</i> <input type="checkbox"/> <i>Otro</i>				
Breve descripción del problema(s):		Identificación de necesidades del niño/familia para el seguimiento de servicios:		
Screening Tool Used			Screening Date	
Nombre del <u>padre</u> o guardián legal			Teléfono	
Domicilio		List any Communication Barriers		
<b>Permiso para ceder Información</b> Yo doy permiso a _____ para comunicarse con el coordinador de salud acerca de los servicios disponibles por parte de (Title V/Child Health Agency). Entiendo que la información será compartida entre (Title V/Child Health Agency), el/la médico remitente y cualquiera de las recomendaciones que están en la lista presentada a continuación. Firma _____ Fecha _____				
<b>Posibles Recomendaciones</b>	<b>The following programs apply as possible referral sources: (may need to change according to your area)</b>			
<b>Servicios de Apoyo para Educación de Padres</b>	PAT HOPEs Stork's Next Support Groups Child Birth Classes NEST Other:			
<b>Consejería Profesional ó Servicios de Salud Mental</b>	Community Mental Health Center Bridgeway Counseling Associates ResCare Other:			
<b>Servicios de Intervenciones y Evaluaciones Temprana</b>	Early ACCESS AEA Child Specialty Clinics Other:			
<b>Programas de Preparación Escolares</b>	Developmental Preschool Early Head Start Head Start Programs Other:			
<b>Tratamiento y Evaluación referente a Abuso de Drogas/Alcohol</b>	ADDS Other:			
<b>Otros Servicios Sociales</b>	Food Stamps/Food Pantries Clothing Assistance General Relief WIC Housing Assistance Domestic Violence Nutrition Education DHS Legal Aid Financial Assistance Employment Services <i>hawk-i</i>			
<b>Transporte</b>	Bus passes Medical reimbursement SEATS Other			
<b>Otros Servicios Relacionados a la Salud</b>	Tobacco Cessation Immunizations Lead Testing Dental HIV Other:			
<b>Referral Follow-up Update: (completed by care coordinator and faxed back to medical practice)</b>				



# It's time to change how we view a child's growth

## Social and emotional growth

..... 5 years  
60 months

..... 4 years  
48 months

..... 3 years  
36 months

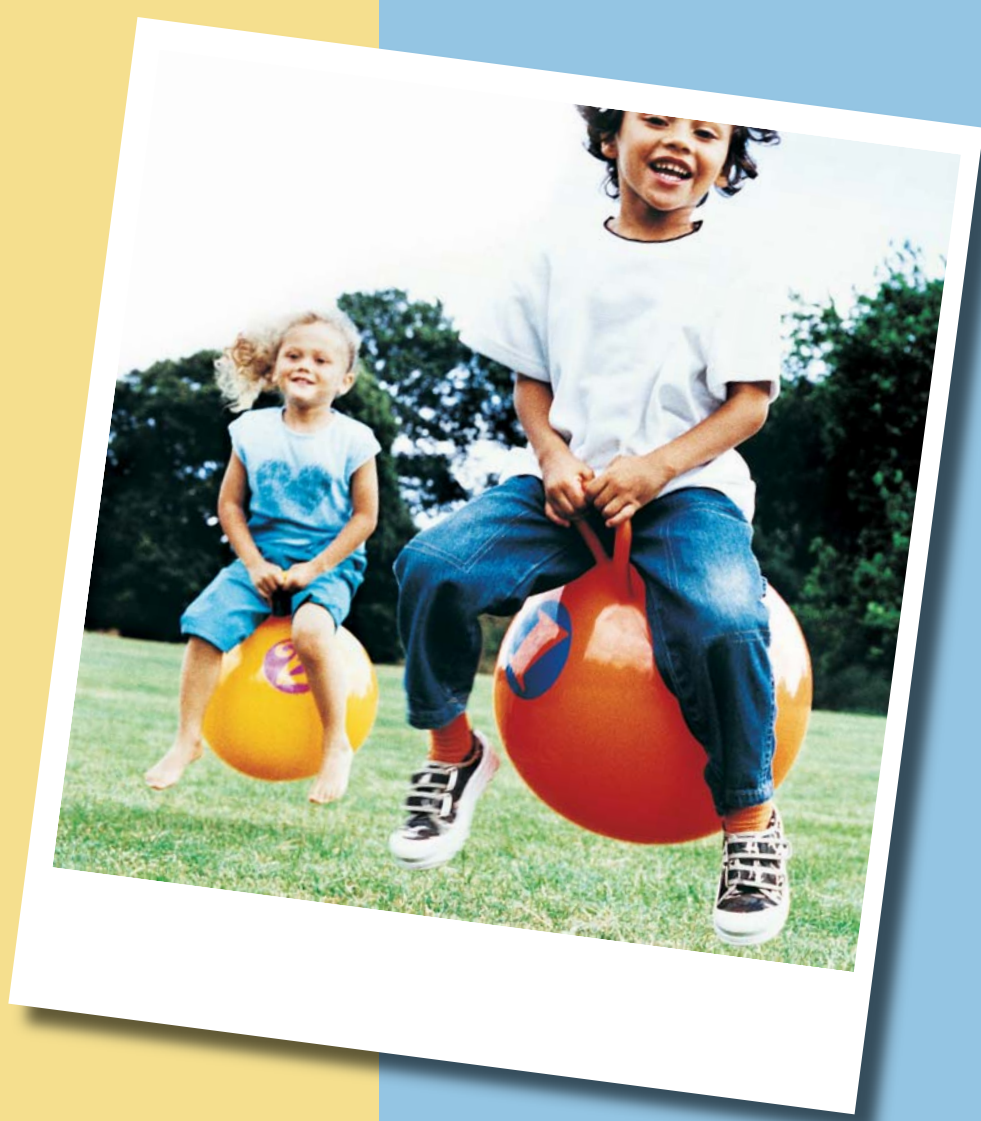
..... 2 years  
24 months

..... 1 year  
12 months

..... 9 months

..... 6 months

..... 3 months



5 years (60 months)

**Social/Emotional/Behavioral:**

- Aware of gender
- Wants to be like his/her friends
- Shows more independence
- Sometimes demanding, sometimes cooperative

**Physical Health/Vision/Hearing/Speech:**

- Dresses/undresses without help
- Communicates easily with others

4 years (48 months)

**Social/Emotional/Behavioral:**

- Can take turns in games
- Interested in new experiences
- Understands concept of counting and may know a few numbers

**Physical Health/Vision/Hearing/Speech:**

- Speaks in sentences, dresses self with help

3 years (36 months)

**Social/Emotional/Behavioral:**

- Spontaneously shows affection for familiar playmates
- Pretend play
- Understands concept of "mine" and "his/hers"

**Physical Health/Vision/Hearing/Speech:**

- Runs easily, bends over easily without falling

2 years (24 months)

**Social/Emotional/Behavioral:**

- Imitates behavior of others, especially adults and other children
- More excited about company of other children
- More aware of himself/herself as separate from others

**Physical Health/Vision/Hearing/Speech:**

- Walks alone, climbs stairs, kicks ball

1 year (12 months)

**Social/Emotional/Behavioral:**

- Shows preference to certain people and toys
- May be shy or anxious with strangers

**Physical Health/Vision/Hearing/Speech:**

- Walks holding on to furniture
- Pulls to standing position

9 months

**Social/Emotional/Behavioral:**

- Imitates sounds
- Says "mama," "dada"

**Physical Health/Vision/Hearing/Speech:**

- Sits well without support
- Transfers object from one hand to the other

6 months

**Social/Emotional/Behavioral:**

- Enjoys social play (playing "peek-a-boo")

**Physical Health/Vision/Hearing/Speech:**

- Rolls both ways (front to back, back to front)
- Babbles
- Explores with hands and mouth

3 months

**Social/Emotional/Behavioral:**

- Smiles when smiles at

**Physical Health/Vision/Hearing/Speech:**

- Raises head and chest when lying on stomach
- Follows moving objects
- Turns head toward direction of sound

### Is your child reaching their developmental milestones? If not, talk to your doctor.

[www.idph.state.ia.us/1stfive](http://www.idph.state.ia.us/1stfive)

1-800-383-3826



Healthy mental development  
in the first five years

1 of out of 6 children experience developmental concerns that could negatively impact the rest of their lives. The earlier a developmental problem is identified, the more you can do to help your child. Talk with your doctor about your child's total development.



## 1st Five Site Coordinator and Director

Identifying a **1st Five** site coordinator is critical to effective program implementation. In particular, a site coordinator needs to have strong leadership skills that include relationship building/networking skills across family serving systems, and a solid understanding of working directly with families from a care coordination perspective. It is not recommended that a site coordinator also takes on care coordination responsibilities if the site is has more than 20 open referrals at a time, but should understand the **1st Five** care coordination model and day-to-day responsibilities so as to lead an effective team. Care coordination requires personal contact with families and providers that allows for individualization of care and family-centered decision making to meet the needs of each family. This communication may be carried out through face-to-face visits, telephone contacts, or written correspondence.

At the individual level, care coordination may involve providing information about available services, assisting clients in making health care appointments, coordinating access to needed support services, coordinating access to health care services and following up to ensure that services were accessed. Site coordinators may need to work flexible hours in order to reach families who are not available during the day.

Site coordinators are primarily responsible for maintaining a strong relationship with participating **1st Five** medical practices. This relationship includes regular communication on referral status and program maintenance. In addition, site coordinators are the faces of **1st Five** in their communities and serve in the capacity as messengers about the importance of young children's healthy mental development to community stakeholders.

## 1st Five Leadership Recommendations

Prepared by the Child and Family Policy Center

### Specific areas of knowledge or experience

For successful and timely implementation, the coordinator should have some **early childhood experience** regarding child development from birth to five.

- The coordinator will be expected, from the project start, to be able to discuss appropriate screening protocols and tools and encourage “buy-in” to help doctors, staff and other stakeholders “get it”.
- Some experience or understanding regarding the culture of a medical practice is needed. Coordinators have to be able to successfully gain access and address underlying and ongoing concerns doctors and staff might have that could stop forward progress.

### Assure accountability and forward movement

Local coordination must include **the ability to move the project ahead and hold others to deadlines**, while assuring accountability to the plans outlined in the grant application.

- There must also be some flexibility and ability by the coordinator and other local team members to change plans and strategies as needed.
- The project must be responsive to external factors in the community and at the state level.
- Most practices will require continuous education and support to successfully integrate screening and referrals into their everyday work.

### Responsiveness

The coordinator **must show a consistent level of responsiveness** throughout the process with all the stakeholders including doctors and staff, state coordinators, evaluators, community representatives and others.

- Timely referrals increase buy-in from the practices as the system rolls out and ongoing communication with other stakeholders is seen as a real strength among sites.
- Provide feedback and lessons learned to state and other **1st Five** initiative site coordinators as well as barriers to referrals and services.

### Resources in the community

There must be accurate and timely **awareness of available services and relationships in the community** in order to identify additional resources or potential referral sources.

- Collecting these services and resources is an ongoing and necessary part of the project. Good referrals can only be made and accomplished when the referral is to a viable, appropriate resource or program.
- The coordinator is often seen as a clearinghouse for barriers and issues that are uncovered during the referral process. Collecting data on barriers encountered is important to finding solutions to these barriers.

### Time for coordination

There must be **support from the oversight organization at the local level**, particularly within management.

- The provision of consistent and appropriate levels of time for project coordination and work is central to the implementation and ongoing success of this initiative.
- The coordinator becomes the face of the project and the primary advocate for this work in the area. The actual time commitment required will vary depending on the number of practices and other factors.

### Promotion

Local sites must have some **ability to promote and explain the importance of the project and be able to convey enthusiasm** around what this will do for kids and families in the area.

- This type of passion is needed to not just bring practices on board but their staff, community planning organizations, funders, parents, legislators, community and state partners and so on.

### Relationship building

A central part of **the success of this project relies on the relationships** already in place or the process of relationship building among all the stakeholders.

- The coordinator must gain the trust of the practices, community programs, families and others.
- The families must be comfortable partnering with the coordinator or the staff who will work through the process with them and share stories and successes as well as barriers and gaps in services or support.



## 1st Five Lessons Learned for Site Coordinators

During the course of the **1st Five** Healthy Mental Development Initiative, site coordinators have provided the project evaluation team at the Child and Family Policy Center with lessons they have learned about how to best implement the **1st Five** model.

### Leadership and dedication:

The grantee organization needs, from the beginning of the implementation process, to identify a dedicated staff to lead these efforts at the site level. This person needs to have the time to give the energy needed for the project from early on in the process. That person has to be available to attend both state trainings and national conferences when appropriate. If the dedicated staff person is not able to attend these training opportunities or to dedicate time up front, it has been shown to delay project start up and work with the local providers. The **1st Five** coordinator should be an enthusiastic, visible representative to medical providers, community resources, and other stakeholders. Marketing **1st Five** will take a lot of time and may be a new type of job activity for many site coordinators. They can get comfortable with it by practicing as much as possible right from the start of the project. Site coordinators should be able to tell stakeholders what **1st Five** can do for them, not just what they can do for **1st Five**. **1st Five** should be a part of their team, “on their side” so to speak.

### Sharing with other 1st Five sites:

Site coordinators have learned to share knowledge, materials, and expertise with other sites as much as possible. There are differences in needs and implementation processes depending on whether the providers are located in a rural or urban setting. Some differences have shown themselves in areas such as the average ages of the patients seen by practices and areas of resource needs such as transportation, parent education, and other supports. Each site is different and must do the best they can with the resources they have available. However, chances are that sites have gone through or are going through similar challenges. Visiting other **1st Five** sites to see their process may be beneficial for sites just starting out or those experiencing difficulties.

### Early childhood expertise:

Implementing the **1st Five** model relies on the time-intensive work of providing education to and building relationships with the staff and doctors at medical practices. While supporting the need for dedicated staff, it also highlights the importance of a coordinator who is able to “hit the floor running” with experience and a knowledge base in the area of early childhood development, surveillance and screening. It does not seem necessary that the coordinator is a RN, but they should have some background that provides them the confidence to talk about early childhood development with medical staff and doctors. The coordinator should be familiar with early brain development and social/emotional development and the effects of family stress and caregiver depression on young children. The **1st Five** state coordinator is able to provide research data for any of these areas upon request. The site coordinator should feel comfortable being the “expert” on these issues with providers and with the community coalition.

### Developing referral resources:

**1st Five** coordinators and their organizations need to be aware of the local and regional resources available and have relationships in place to access resources, addressing any barriers as they are identified. Site coordinators must become knowledgeable about community resources for people of all ages before implementing the project. Title V child health agencies may already know quite a bit about their communities, but the complex issues unearthed by **1st Five** often require the site coordinator to further develop options for referring families. Site coordinators have found that building relationships with these referral resources and including them in community coalitions will help to promote the goals of **1st Five**, as well as aid in quick turnaround for referrals. Providers may not be aware of all the reasons they can refer to **1st Five** at first, but can learn quickly with the help of a communicative and well-connected site coordinator. Becoming a **1st Five** provider may encourage a physician to look at social issues more closely with all of their patients. The **1st Five** site coordinator may become their safety net, providing them with a broad range of referral options.

### **Sustainability:**

Site coordinators need to think about sustainability from the start and diversify funding sources and stakeholders. Having multiple funding sources increases the long-term sustainability of the **1st Five** project. When one source of funding decreases or disappears a site will still have funding from other areas.

### **Communicating with medical practices:**

The business model and office culture of practices must be respected. Site coordinators have learned to try to fit **1st Five** within the existing system of doing things and not to make assumptions about how a practice does things, even when they are part of a larger system already working with **1st Five**. It is important to meet the provider and their staff “where they are” and to educate, build relationships and provide encouragement consistently over time. Sites have learned that just because the doctor in a practice is supportive of the project does not mean that the office staff will make it a priority. Clinic managers may avoid implementing the project as it may seem to be more work for them. Reluctant practices may come on board only after they hear positive results from other practices. Other times they may not come on board until the practice has to deal with a child they do not know where to refer to. Site coordinators have learned that continuing to work with reluctant practices on other issues as needed may get them on board eventually. Keeping a log of communication with practices helps site coordinators to identify what works and to make changes as necessary. Once a champion is identified in a practice it is still very important to continue the conversation and relationship building not only with that champion, but with other staff who will actually be implementing the **1st Five** program work. Responsive technical assistance helps to avoid frustration within the practice as well. Most importantly, site coordinators have identified following through on what they say they are going to do as key to building long-term relationships with practices.

### Agency changes:

The approach to care coordination service taken by a Title V child health agency will change as a result of becoming a **1st Five** site. All staff must become more knowledgeable about factors affecting social and emotional development. Several **1st Five** sites have trained their staff on screening for family stress and caregiver depression and found it challenging, but beneficial to the goals of their agencies. Being able to identify and provide referrals for these issues will help any Title V agency better serve families.





## 1st Five Getting Started

The four main objectives of 1<sup>st</sup> Five Healthy Mental Development Initiative are to:

1. Increase the number of primary care providers who are using a standardized developmental screening tool to identify children who are at-risk or need low level interventions.
2. Provide infrastructure building activities such as working with primary care providers and nurse managers on the implementation of developmental surveillance and screening.
3. Educate EPSDT providers and other community providers to increase the knowledge of the importance of developmental screening and social determinants of health.
4. Provide care coordination services to families and provide feedback on referrals to primary care providers.

### **Assess care coordination and referral processes for young children in your community:**

- Who links physician offices with community-based services?
- Is there a community resource directory already available? What entity maintains this list?
- Who can provide input on community resources? Service providers? Agency clients?
- Do physician practices receive follow-up information from social service/community-based referrals?
- Do parents receive depression or stress screening at well-child exams?
- Do pediatric providers know where to refer parents for adult depression?

### **Identify your local coalition:**

- How can you elicit support from leadership in your organization and in your community?
- Who are your stakeholders?
  - Physician groups/associations/chapters
  - Nurse associations/physician assistants
  - Payers – Medicaid and private insurers
  - Community-based service providers and their funders
  - Title V/ Public Health
  - Part C/Early Intervention services
  - Legislators/the Governor's office
  - Child advocacy/public policy groups
  - Parents/Family advocates
  - Local AEAs



- Where are your stakeholders on this issue? Do they need more education or are they supportive and ready to act?
- Who will convene the stakeholders and lead this effort?
- Who is the champion for the issue? Who can affect policy change?
- Who will lead practice change? Who will be your biggest promoter?
- Who or what will be your biggest barrier?

### **Lunch-n-Learn/Coalition meetings:**

- Examples of previous topics from 1<sup>st</sup> Five Sites:
  - Refugee and Immigrant Needs
  - Toxic Environments for Children
  - Fatherhood and Supporting Young Children's Development
  - Oral Health Services
  - ASQ-3 trainings
  - Contemporary Iowa Child Health Care
  - Screening for Early Autism Detection
  - Screening for Maternal Depression, Family Stress and other risk factors
  - Family 2 Families Program Support Services for families with children with special health care needs
- How to discuss sensitive topics with parents
  - How to deliver difficult news to parents
  - How to discuss culturally sensitive issues
- Who comes:
  - Mental health providers, primary care providers, AEA's, school districts, non-profits with similar interest in supporting families, those who they refer to, similar interests in advocacy, 0-3 provider population, family support programs, community health centers, child advocacy support programs
- Lessons learned:
  - Give adequate advance notice, require RSVPs, keep and update mailing list, send out reminder, provide food, ask for dietary needs, vary menu, follow up with attendees



## 1st Five Possible Referral Resources

The following is a list of possible community resources and service providers. Site coordinators should develop a detailed list of these types of resources for referring children and families. Other needs may be identified in a specific community as well.

- Mental health services for children
- Mental health services for adults
- Early ACCESS
- Area Education Agency
- Head Start/Early Head Start
- Lead testing
- Vision screening
- Dental care for children
- Dental care for adults
- Immunizations
- Well-child care providers
- Insurance resources
- Other health-related referrals for the child (UIHC, CHSC, etc.)
- Other health-related referrals for the family
- Food (WIC, food banks, food stamps)
- Maternal depression support
- Transportation resources
- Baby/child supplies
- Case management services
- Counseling
- Child development information
- Child care assistance
- Housing
- Financial assistance
- General needs (energy assistance, furniture, clothing, etc.)
- Child abuse prevention services
- Employment/education
- Parenting support
- Home visiting programs (PAT, HOPES)
- Substance abuse treatment

To view a model of a Community Resources Directory and the kinds of information catalogued for community agencies, go to [www.iafamilysupportnetwork.org](http://www.iafamilysupportnetwork.org)



## 1st Five Care Coordination Protocols

*The following care coordination protocols come from ones currently used in the 1st Five implementation sites. They are examples of how your agency can go about organizing, implementing, and explaining the 1st Five care coordination protocols. The average caseload for a full-time care coordinator is typically 25-35 referrals at a given time.*

### • **Responding to a Referral**

- Identify the purpose of responding to a referral
  - Examples from other agencies
    - ♦ The purpose of the protocol policy for [agency name] is to:
      - ◆ Ensure procedural consistency in 1<sup>st</sup> Five staff response to incoming participant (child and/or family) referrals.
      - ◆ Ensure superior customer service to participants and referral sources.
      - ◆ Ensure consistent training for new staff.
- Provide a step-by-step plan of the general procedure
  - Logistics:
    - Who will be taking the 1st Five incoming referrals? Will it be 1st Five staff or someone else from your agency?
    - Will they be received via phone, e-mail, or fax?
    - Where will the incoming referrals be kept?
    - Examples of how other agencies are doing this:
      - ◆ If you take a call regarding a 1st Five referral:
        - Fill out a 1st Five tab in CARES
        - If you regularly answer the phone, have referral sheets at your desk
        - Collect all information requested on the sheet
      - ◆ Maintain a 1st Five Referrals Folder or mailbox where incoming referrals will be kept. Designate a location for the folder such as in the team leader's mailbox or office.
      - ◆ Place the completed referral in the 1st Five site coordinator's mailbox or on the 1st Five site coordinator's desk.
      - ◆ Check e-mail and/or the fax machine for incoming referrals.
        - Designate roles
          - Who will be checking incoming fax referrals, the mailbox, or folder?
          - Who will keep track of the referrals?
          - How often will they need to be checking for incoming referrals (e.g., three times per work day)?



- When the agency receives a referral:
  - ◆ Establish a follow-up schedule for contacting the family such as: a primary contact call will be placed within 48 hours (or two business days of referral).
  - ◆ When contact is made with the participant, care coordination staff should provide them with a description of the program and the benefits they will receive if they choose to participate.
  - ◆ When a family chooses to participate in the program, a time to complete the initial paperwork should be scheduled. This can occur during the initial phone call, on a home visit, office visit, other visit or additional phone call can be arranged per the wishes of the family.
  - ◆ When meeting with the family, care coordination staff will complete the necessary agency forms (such as the agency **Intake Form** and **Consent to Release Information**) and will compile a comprehensive needs list based on the physician's request and the participant's needs.
  - ◆ Based on the needs list, care coordination staff and family will discuss appropriate community referral sources or further medical care and make plans regarding contacting appropriate providers. The family will be encouraged to make an appointment with the resource, or **1st Five** will assist the family with obtaining or keeping an appointment.
  - ◆ The family will be given **1st Five** contact information, in case questions or needs arise.
  - ◆ When scheduling a home visit, update the outlook calendar to reflect the date and times care coordination staff will be out of the office.
  - ◆ Care coordination staff will follow up with the referring medical provider to let them know the status of the referral process at that time or as the physician has requested (such as which resources have been linked with the family or if the family refused services).
  - ◆ Documentation will be made of any care coordination service through EPSDT provided in the Child Adolescent Reporting System (CAREs).
  - ◆ Care coordination staff will follow up with the family regarding the status of those referrals.

When your agency makes a referral:

- ◆ The original should stay with the care coordinator to be kept and used in the participant's ongoing file.
- ◆ Give a copy to the **1st Five** coordinator to serve as a tracking record.
- ◆ Fill out any other necessary agency-specific forms when making a referral.

Healthy mental development in the first five years



- Form of Communication:
  - ◆ Forms of communication and contact with participants include phone calls, mailings, home visits, office visits and other visits (visits occurring in a neutral location such as a library).
  - ◆ If an address is available the **Initial Letter to Families** is mailed within 24 business hours. This can count as initial contact with the family.
  - ◆ If the potential participant has both a phone number and an address, the care coordinator will make six attempts to contact the potential participant, three phone calls and three mailings. The mailings are the **Initial Letter to Families; Follow up Letter to Families**; and in the case a family was not reached, the third mailing is a letter stating that due to failure to obtain contact, **1st Five** will refer the family back to the referral source.
- Follow-up Contact Schedule:
  - ◆ Children and families who have been identified through assessment by a physician, or who have expressed a need for assistance from **1st Five** should receive follow-up contact within the intervals listed below, unless the physician specifically states otherwise, and gives an alternate interval.
  - ◆ Families should receive a follow-up contact within the following time intervals:
    - 1st Contact:
      - Within twenty-four business hours (one business day) following referral or identification of the concern or within 48 hours (two business days) following referral.
    - 2nd Contact:
      - Two weeks following referral or identification of the concern.
        - Within two weeks following the successful follow-up interaction with the family, contact them again to see how they are doing. For instances where follow-up care or referrals were indicated, determine whether follow-through was completed.
        - A sample question to ask includes:
          - ◆ *Were you able to make a connection with the \_\_\_\_\_ (place or person) that \_\_\_\_\_ (referring entity) referred you to?*
        - If the family has not followed through, offer to assist them to connect with the referral source.
    - 3rd Contact:
      - Every month for six months (or PRN) following referral or identification of the concern.
        - Contact the family again to determine whether they followed through with any resource contacts or



appointments. If they have not followed through, offer to assist them to connect with the referral resource.

- If services were obtained, determine whether the services are meeting the needs of the child referred and/or the family's needs, and whether services are continuing.
- If services are not meeting the needs of the family, **1st Five** will link them with additional resources, or will advocate on the family's behalf with the resources and physician.
- Sample questions to ask include:
  - ◆ *Were you able to make a connection with the \_\_\_\_\_ (place or person) that \_\_\_\_\_ (referring entity) referred you to?*
  - ◆ *Have you had any concerns about your child's health, learning, development, or behavior since our last conversation six months ago?*
  - ◆ *Are you going to \_\_\_\_\_ (primary care provider) for care other than well child exams? If so, what care are you receiving?*
- ◆ All **1st Five** contact information will be included with each contact.
- ◆ Any and all follow-up activities or phone calls to physician or family will be documented in CARES, the paper chart, and the database.
- ◆ If participants refuse services or do not respond after three attempts, the physician will be notified of the refusal of service. Refusal will also be charted in CARES, paper chart, and database.
- ◆ Identified concerns that require three attempts at follow-up by telephone:
  - **Parental Depression** – if caregiver answers “**often**” to the following:
    - “In the past month have you felt down, depressed, or hopeless?”
    - “In the past month have you felt little interest or pleasure in doing things?”
  - **Stress** – if caregiver answers “**severe stress**” to the following:
    - “How much stress are you and your family under at this time?”
  - **Stress** – if caregiver answers “**severely stressful**” to the following:
    - “How stressful is caring for your child?”
  - Mental, physical, or behavioral developmental concerns identified by parent or physician.
  - Growth & development concerns identified by the parent or professional for any children in the family.





- Early ACCESS and Child Health Specialty Clinic referrals
- Any requests from the medical offices for follow-up on children

- **Documentation**

- CAREs

- The **1st Five** site coordinator will always record needs and services in CAREs following guidelines in the CAREs User Manual and in progress notes. The needs and services will also be documented in the paper chart and database.
- CAREs documentation will include: patient and family information, referral source, medical home information, dental information, medical and dental barriers, Early ACCESS information, if eligible, services and needs documentation, periodicity screening, and service follow-up information.
- Maternal depression referrals will be tracked in their own database, and the follow-up contacts will be made at the same intervals listed above.

- **1st Five** Participant Folder File

- General Overview:
  - Every **1st Five** participant will have their own file folder. This folder will contain the referral form, all documentation regarding contact with the participant, medical provider, community provider etc, releases of information and other documentation necessary for the provision of services.
    - ◆ Here your agency can specify how to organize the folder such as: the referral form will be filed on the inside left side of the participants file, or the form X will be filed on the inside right side of the participant file, etc.
- Filing and Charting:
  - Paper and electronic files will be kept for each child and/or family. All referrals will be tracked and information stored in a database.
  - Maternal Depression referrals will also have a paper chart.
- Paper Charts can include:
  - Demographics Sheet
  - Contact Schedule
  - Follow-up Sheets – Family
  - Screening and Referral Sheet – Physician
  - Depression Screening Tool – Physician
  - Follow-up Sheets – Physician
  - Patient Checklist
  - Copies of letters mailed or any other type of communication



- Any other information the **1st Five** Coordinator chooses to include

- **Maternal Depression Screening**

- Screening Staff
  - Which individual(s) on staff is (are) best qualified for providing the screening?
- Screening Tool
  - The Edinburgh Postnatal Depression Scale (EPDS)
- Cut-off Score
  - 11; any score greater than 11 will be considered a need for further evaluation or treatment.
  - A score of 1 or more on item #10 indicates a need for immediate referral.
- Screening Schedule
  - Initial visit to Maternal/Child Health
  - 28 weeks gestation
  - Well-child exam (**1st Five**)
  - Within 6-8 weeks after Mom is home with the baby
  - Postpartum
  - **If a score is elevated, but below 11, the EPDS will be repeated at the next visit.**
- When to refer
  - ≤ 11 results are normal and no additional action is needed. A score of 11 or more will be considered elevated, or when the patient states she is feeling signs or symptoms of depression or elevated stress levels.
  - 11-13 results are borderline, repeat the EPDS in 2 weeks.
  - **14-19 results are significant – the score should be reported to the patient’s primary care provider with her written consent.**
  - **≥ 20 major problems are indicated and immediate action is required. Refer to client’s physician and refer to recognized mental health provider.**
  - **A positive response to Item #10 – do further risk assessment and refer to necessary source (see below).**
- Referral procedure
  - Who will make the referral?
    - The staff member providing the screening will make the referral, after consulting with the program manager or program director. An attempt will be made to contact the primary care provider of all women who have an elevated EPDS score as indicated above, as well as the primary care provider of their children. Staff members will obtain patient’s written consent prior to informing the primary



care providers. The staff member will explain that this procedure can help the caregiver's primary care provider know how to better support the caregiver. If patient refuses consent, patient should be strongly encouraged to contact their primary care provider.

- Identify other possible resources in the community that the patient can access such as: mental health professionals in the area, parent support groups, clinics, hospitals, etc.
- Keeping records
  - EPDS Form Placement
    - ◆ All screening personnel will be given a folder with the EPDS forms and related documentation. Completed documents will be placed in the client's record.
    - ◆ Data tracking will include use of the EPDS at recommended intervals, number of referrals based on the assessment, and the number of referrals accessed by clients. This information will be reported in the year-end **1st Five** data report.
- Procedures for Elevated Item #10 on EPDS (Suicide Risk Assessment)
  - Assessment Procedures
    - The first step in a suicide risk assessment should be to inquire about the elevated item documented on question #10.
      - ◆ **"Have you felt so low that you've thought life is not worth living?"**
    - If the answer is in any way affirmative, the active intent should be determined.
      - ◆ **"What types of things have you considered doing?"**
      - ◆ **"Where would you do this?"**
      - ◆ **"How strong is your intent?"**
      - ◆ **"Have you been drinking or using other substances lately?"**
      - ◆ **"When do you usually have these suicidal thoughts?"**
      - ◆ **"Have you heard voices telling you to hurt yourself?"**
      - ◆ **"How long do these thoughts last once they start?"**
      - ◆ **"Have you made plans for after your death?"**
    - If the client does have active intent, you should ask whether they have the means to carry out the plans they have devised.
      - ◆ **"Are there means available for you to carry out your plan?"**
      - ◆ **"Is there anyone or anything to stop you?"**
      - ◆ **"Are there other possible solutions that you've considered?"**
      - ◆ **"What do you look forward to, despite your current situation?"**



- If staff are concerned that a client is a suicide risk, they should insist that the client go to their doctor or one of the local mental health resources.
- If the client refuses, and staff suspect they are truly a threat to themselves, the authorities must be notified.
- Possible Actions—depending on level of risk
  - Checking in with client.
  - Providing client with emergency number.
  - Contacting a family member (with client's permission)
  - Contacting a health professional (with client's permission)
  - Contacting your supervisor.
  - **NEVER leave a client if you feel she is at risk until appropriate help is available.**
- Have a list of emergency contacts and telephone numbers in case you need to call someone right away.



## **Iowa Recommendations for Scheduling *Care for Kids* Screenings Development and Behavioral Assessment for Title V Child Health Agencies**

Iowa Recommendations for Scheduling *Care for Kids* Screenings (EPSDT Periodicity Schedule) was revised in July 2009 to better align with *Bright Futures* Third Edition, the American Academy of Pediatrics Guidelines for Health Supervision of Infants, Children, and Adolescents. The revised schedule includes delineation of the development and behavioral assessment section into five categories: developmental surveillance, developmental screening, psychosocial/behavioral assessment, autism screening, and alcohol and drug use assessment. This document is designed to provide Title V Child Health agencies with a brief summary for each category in the 'development and behavioral assessment' section of Iowa's Periodicity Schedule.

For more detailed information about developmental and behavioral surveillance and screening tools, see the Iowa EPSDT *Care for Kids* Provider Website at [www.iowaepsdt.org](http://www.iowaepsdt.org). A chart of screening tools found on this website is attached. Helpful information is also provided in the Medicaid Screening Center Provider Manual at [http://www.dhs.state.ia.us/policyanalysis/PolicyManualPages/Manual\\_Documents/Provman/scenter.pdf](http://www.dhs.state.ia.us/policyanalysis/PolicyManualPages/Manual_Documents/Provman/scenter.pdf) under Developmental Screening and Mental Health Assessment.

### **1. Developmental surveillance:**

- For agencies completing the full well child exam: Developmental surveillance is a component of the full well child exam. If you are using the **Iowa Child Health and Developmental Record (CHDR)** forms, these questions would be found in the 'Developmental' section. There is no separate billing for this service, as it would be included as part of the physical exam. (See <http://www.iowaepsdt.org/ScreeningResources/CHDR.htm> for the Iowa CHDR forms.)
- For agencies referring to a medical home for the well child exam: Completion of the of the **CHDR's** 'Developmental', 'Social History', and 'Anticipatory Guidance' sections have been approved for billing as a care coordination service. Documentation for the care coordination service must report use of the **CHDR** and reflect the scope of the service, findings from the family, and any referrals that may result.

### **2. Developmental screening:**

- In Iowa, there are several tools that are recommended. Our Title V Child Health programs were offered training on the **Ages and Stages Questionnaire (ASQ)** and **Ages and Stages S-E (ASQ SE)**. There are other developmental screening tools listed at [www.iowaepsdt.org](http://www.iowaepsdt.org) such as **Bayley Infant Neurodevelopment Screener**, **Brigance Infant and Toddler Screen**, and **Parents' Evaluation of Developmental Status (PEDS)**.
- The developmental screen may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

### **3. Autism screening:**

- In Iowa, there are two recommended tools, the **Modified Checklist for Autism in Toddlers (M-CHAT)** and the **Pervasive Development Disorders Screening Test II (PDDST II)**. (See [www.iowaepsdt.org](http://www.iowaepsdt.org).)
- The autism screen may be billed to Medicaid by Title V Child Health agencies using Code 96110. (Note that this code can only be billed once per visit (so at 18 months when both the developmental screen and autism screen are due, you could only bill one 96110 for the screenings provided). The autism screen is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

#### 4. Psychosocial/behavioral assessment:

- **Psychosocial/behavioral surveillance**

- For agencies completing the full well child exam, psychosocial/behavioral surveillance is provided at each visit as a component of the full well child exam. If you are using the Iowa **Child Health and Developmental Record (CHDR)** forms, these questions would be found in the 'Social History' section. There is no separate billing for this service, as it would be included as part of the physical exam. (See <http://www.iowaepsdt.org/ScreeningResources/CHDR.htm> for the Iowa CHDR forms.)
- For agencies referring to a medical home for the well child exam: Completion of the of the **CHDR's** 'Developmental', 'Social History', and 'Anticipatory Guidance' sections have been approved for billing as a care coordination service. Documentation for the care coordination service must report use of the **CHDR** and reflect the scope of the service, findings from the family, and any referrals that may result.

- **Psychosocial/behavioral screening**

- Psychosocial/behavioral screening may be provided using the **Pediatric Symptom Checklist** (See [http://www.brightfutures.org/mentalhealth/pdf/professionals/ped\\_symptom\\_chklst.pdf](http://www.brightfutures.org/mentalhealth/pdf/professionals/ped_symptom_chklst.pdf).) There are two versions, a parent report and a youth self report (Y-PSC) for adolescents ages 11 – 18. The **Pediatric Symptom Checklist, Youth Self-Report (Y-PSC)** may be used to provide a mental health screen for 11-18 year old patients during well visits, sports physicals and other routine office visits.

Psychosocial/behavioral screening may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

#### 5. Alcohol & drug use assessment:

- *Bright Futures* recommends the **CRAFFT Screening Tool**. The **CRAFFT** is a behavioral health screening tool for use with children under the age of 21 and is recommended by the American Academy of Pediatrics' Committee on Substance Abuse for use with adolescents. It consists of a series of 6 questions developed to screen adolescents for high risk alcohol and other drug use disorders simultaneously. It is a short, effective screening tool meant to assess whether a longer conversation about the context of use, frequency, and other risks and consequences of alcohol and other drug use is warranted. (See <http://www.ceasar-boston.org/CRAFFT/index.php>).

Use of the **CRAFFT Screening Tool** may be billed to Medicaid by Title V Child Health agencies using Code 96110. It is billed separately from a well child exam. This service requires the administration of a recommended tool, interpretation and report of the results of the screening, anticipatory guidance, and any referrals that may result from the screen. Documentation of each of these elements must be included in the client chart.

Agency: \_\_\_\_\_

Name(s): \_\_\_\_\_

**Title V Agency Self-Assessment on the Following Aspects of  
Child Health Care Coordination:**

- 1. Access to Care**
- 2. Value of Preventive Services**
- 3. Screening for Social/Emotional Development**
- 4. Referral and Follow-up**
- 5. Medical and Dental Home**
- 6. Community Awareness of Title V EPSDT Care  
Coordination Services**

This self-assessment is intended to assist agencies with determining baseline data on the current status of child health programs in relation to six aspects of care coordination. This baseline data can help develop agency-wide care coordination strategies for the next 1-3 years.

We recommend that agencies use a coordinated team approach when completing the assessment. At a minimum, the EPSDT Coordinator, Child Health Coordinator, and I-Smile Coordinator should fill this out together if these positions are filled by separate individuals. However, to capture a more complete agency picture of care coordination activities, it is recommended that along with the EPSDT Coordinator, I-Smile Coordinator and the Child Health Coordinator, the EPSDT care coordination team and other child health team case managers are also included when completing the assessment. *(Since only one assessment is requested per agency, the individuals completing the survey will need to come to a group consensus if opinions differ. Additionally, if your agency subcontracts for care coordination services, then incorporate an assessment of subcontractor care coordination services with your own agency assessment).*

Please provide an honest assessment of where your care coordination services are currently. There are no right or wrong answers. Your answers will help form the basis for your agency care coordination strategies.



**NOTE: For the purposes of this assessment, the term *care coordinator* includes all child health professionals who provide enabling services for child development services and preventive care, which includes informing and care coordination.**

**Access to Care:**

**1. Care coordinators inquire into the health insurance status of every child health client.**

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**2. Care coordinators inquire into the dental insurance status of every child health client.**

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**3. Care coordinators assess the degree to which health care coverage allows families to establish a medical and dental home, obtain specialty care, obtain medications and other related health care.**

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**4. The care coordinators assist the family with overcoming access to care barriers for the child health client as these barriers arise.**

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

### Value of Preventive Services

**5. A)** Which type of guidance is/are reflected in your agency protocols that delineates how care coordinators discuss the value of preventive care with clients during informing and care coordination visits/encounters? (circle all that apply)

1	2	3
General guidance	Specific guidance	Written Script

**B)** If agency protocols are in place on how to give families guidance regarding the value of preventive services, the percentage of time staff apply these protocols while interacting with families is...

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**6.** Care coordinators educate families on the components of a well-child medical and dental exam and the importance of regularly scheduled check-ups.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**7.** Care coordinators discuss the importance of interperiodic screens (between recommended screenings) that may be necessary to determine the existence of a suspected physical or mental illness or condition.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

---

### Screening for Social/Emotional Development

**8. A)** Care coordinators ask families prior to the well child visit, "Do you have any concerns about your child's health, development, or behavior?"

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**B)** If concerns are identified, care coordinators encourage caregivers to share these same concerns with the doctor during the visit.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**C)** Care coordinators provide guidance on how to talk with providers about these concerns if the caregiver appears uncertain.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**9. A).** For younger child health clients, ages 0-5 years, care coordinators educate families on the importance of social/emotional development during these years and

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**B).** For younger child health clients, ages 0-5 years, care coordinators share tips for how caregivers can support this critical developmental period.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**10.** When providers identify a potential developmental problem with a child health client and determine the need for additional developmental screening, care coordinators are knowledgeable about resources for linking families to the appropriate services.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

---

## Referral and Follow-Up

**11.** Care coordinators assess the degree to which families are knowledgeable about resources sufficient to meet each individual child's health, learning, and social/emotional needs.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**12.** When families have an identified need indicated for a referral, your agency applies the following strategies for the referral:

**A)** Inform a family who to contact.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**B)** Make a call on behalf of the family.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**C)** Provide a written referral.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**13.** Care coordinators arrange follow-up on missed appointments.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**14.** Care coordinators follow-up with families to see if all necessary medical and dental diagnostic and treatment services have been received where a referral was provided.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**15.** Care coordinators provide follow-up education and monitoring of medical and dental treatment/care plans.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**16.** If a release of information has been obtained between the provider and the Title V EPSDT program, care coordinators provide follow-up information to the provider's office on the status of the original referral.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

---

## Medical and Dental Home

### Medical Home

**17.** Care coordinators educate families on the concept and importance of a medical home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**18.** Care coordinators develop an updated list of local health care providers who accept Medicaid clients and share this list with families who do not have a medical home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**19.** Care coordinators provide care coordination services to link families to a medical home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**Dental Home**

**20.** Care coordinators educate families on the concept and importance of a dental home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**21.** Care coordinators develop an updated list of dental providers who accept Medicaid clients and share this list with families who do not have a dental home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**22.** Care coordinators provide care coordination services to link families to a dental home.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

### **Community Awareness of Title V EPSDT Care Coordination Services**

**23.** Community agencies, organizations, providers, and individuals providing direct care clinical services are aware of and refer to the Title V EPSDT/*Care for Kids* program for assistance with care coordination for their child health clients.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely

**24.** *Care for Kids* staff work collaboratively with providers and agencies to facilitate a streamlined referral and follow-up process for child health clients.

1	2	3	4
Always (upon every admission)	Most of the Time ( $\geq 70\%$ of the time)	Sometimes (50% of the time)	Rarely



## 1st Five Barriers to Care Coordination

During the course of implementing and sustaining the **1st Five** Healthy Mental Development Initiative, site coordinators have encountered various barriers to meeting the needs of children and families in their communities. Data on some of these barriers and possible solutions have been collected through **1st Five** evaluation activities by the Child and Family Policy Center.

### Accessing health care services for Medicaid patients:

**1st Five** site coordinators have sometimes had difficulty finding services for children receiving Title XIX in their communities. For example, the Visiting Nurse Association of Dubuque acts as a gate-keeper between Medicaid patients and area pediatricians who accept limited numbers of Medicaid patients. VNA works to assure medical practices that any new patients will be able to keep appointments. For most local Medicaid patients a pediatrician is not an option; VNA refers them to the local Federally Qualified Health Center (FQHC). The FQHC does not have a pediatrician on staff, but will refer patients with chronic conditions or in need of specialty care to the University of Iowa Hospitals and Clinics. At the same time, VNA also works to advocate policy change by hosting regular meetings of the Dubuque County Board of Health Access to Care Subcommittee, which occasionally includes local legislators. This method of advocacy has seen progress, with one local provider now becoming a *hawk-i* provider. Greater provider cooperation with the **1st Five** Initiative is a possible result as well.

### Transportation:

Lack of available transportation services is a major barrier to access to care, especially in rural areas. Many rural communities lack bus service to even local appointments. EPSDT transportation fills some of the gaps. Out-of-town transportation reimbursement provided by the Department of Human Services is often not helpful, because families do not have access to a vehicle or do not have the funds up front. Site coordinators have been able to locate other community resources, such as Bridge to Care in Taylor County. Advocating for greater transportation access is a key part of community coalition work for **1st Five** site coordinators.

### **Obtaining birth certificates for insurance applications:**

Families often put off completing Title XIX and other applications, because they do not have birth certificates available. Finding funding sources for **1st Five** families to purchase out-of-state birth certificates can be difficult. **1st Five** site coordinators have no dedicated funding source for this purpose, but have sometimes been able to use community foundations, churches, and other funding sources. Once families are enrolled in Medicaid they are more likely to maintain a medical home and have access to a variety of medical services.

### **Lack of follow-through from families:**

**1st Five** site coordinators have been frustrated by families who decline services, as well as families that do not respond to phone calls or do not follow-up with the referrals made. Letters and phone calls are often not sufficient for engaging some families. Some site coordinators have improved follow-through with these families by making home visits themselves or by referring the family to local programs that make home visits. With families that are difficult to engage, consistency and speed is often important. Many of these difficult families move or change phone numbers quickly, making follow-through on the part of the site coordinator paramount to assisting these highly vulnerable children and families.

### **Lack of local resources:**

When children need to be referred to a specialist, local providers are often not available. University of Iowa Hospitals and Clinics and regional Child Health Specialty Clinics are the usual referrals for children in need of specialized care, but this often creates difficulty with securing regular transportation to appointments. In addition, CHSC has recently experienced cutbacks, closing some offices and increasing the wait time for services at others.

### **Summer services:**

Area Education Agency services are often not available in the summer, which can be frustrating for **1st Five** families and site coordinators. Some site coordinators have been able to refer families to similar services from other providers, such as speech language pathologists.

### **Lack of commitment and referrals from medical practices:**

Being comfortable, enthusiastic, and consistent in communicating with area medical practices can be difficult for some site coordinators. Providers often express interest, but lack commitment and referrals. The site coordinator's job is to assist practices in implementing and sustaining surveillance, screening and referral processes. Some practices implement surveillance and screening but use their own care coordination process for most referrals; if this is the case, site coordinators continue to maintain a relationship with that practice and assist them with whatever they may need in the future.

Making regular face-to-face and telephone communication efforts with practices, both those yet to commit and those already committed, is one of the most important pieces to implementing and sustaining the **1st Five** model. Site coordinators are busy, medical practices are busy, the weather gets in the way. These are all barriers to building the public-private partnership. However, site coordinators are expected to be in contact with practices weekly or monthly, and perhaps quarterly when a practice is consistently providing a maximal number of referrals.

When staff turnover occurs in medical practices, site coordinators may need to make extra contacts to provider offices to assure continuity. Site coordinators have learned that it is important to ask providers what you can do to help them fully implement the **1st Five** model. Providing lunch 'n' learns for the whole practice can help alleviate communication barriers within the practice. Taking advantage of provider training offered by **1st Five's** medical consultant, Dr. Mary Larew, has been successful in getting practices on board for some site coordinators.

Visiting Nurse Services of Iowa has been particularly consistent in attempting to engage a large practice in their area. The long-term experience of VNS indicates that not giving up in the face of frustration pays off eventually. Even when a practice is reluctant at first, word of mouth from other participating providers can encourage buy-in in the future. Providers also may not recognize all of the possible reasons for referral to **1st Five**. Site coordinators have learned to emphasize the wide variety of services that **1st Five** refers families to as a major benefit and convenience to practices.



### **Lack of mental health providers:**

Some of our site coordinators have had difficulty finding mental health services to refer families to. Finding providers willing to see children under 5 is especially difficult, as is finding providers who accept Medicaid payment. When services are available, the wait for an appointment is often so long that follow-through by the families becomes less likely. Site coordinators have exhaustively researched alternative resources across their service areas that may provide mental health services.

### **Spanish-speaking families:**

Many **1st Five** sites do not have bilingual employees for interpreting with Spanish-speaking families. Site coordinators must rely on telephone interpretation services which can be an impediment to building rapport and a strong trusting relationship. Spanish speaking mental health providers and other services are also not available in many communities. Because some types of resources are limited to legal residents, resources and services for undocumented workers and their families can be hard to find. The families of undocumented workers can be extremely vulnerable, but **1st Five** coordinators continue to make an effort to find accessible services for these families, as well as advocate at the community, state and federal levels on their behalf.



## How the **1st Five** Model Can Enhance Existing Title V Care Coordination

### 1) Identify Potential Primary Care Partners:

- Building relationships with and receiving referrals from local primary care providers is possible for any Title V agency. One option for choosing a potential partnering provider is to identify through CARES, a common primary care provider that a large number of child health clients go to in the area. The care coordinator can enlist that provider's help in referring children and families in need of care coordination services.
- Title V agencies can bill for these referrals from primary care providers. Documentation in CARES service notes of a provider's referral serves as evidence of the medical necessity of care coordination services. Additionally, as long as care coordination includes discussion about medical-related services for the child and it is documented in the notes, then care coordination can also be billed when addressing family stress issues such as housing and other financial assistance services since these impact the mental health and well being of the child and family, as identified by the practitioner's referral. *(For more information, please refer to the Child Health Services Summary)*

### 2) Integrate Child Health and Development Record (CHDR) surveillance questions and developmental screening (ASQ) into routine care coordination:

- Care coordinators can administer CHDR questions on social-emotional development, family stress, and caregiver depression and/or developmental screenings (such as the ASQ\*) to the children they serve to better identify concerns and referrals for these families. Documentation of these screenings serves as evidence for the medical necessity of care coordination services. When concerns are identified, encourage parents to talk with their child's doctor about these concerns. Additionally, share with parents free, downloadable family handouts that address their behavioral or developmental concerns. Examples of evidence-based tools are available at:  
<http://www.vanderbilt.edu/csefel/resources/family.html>.



### 3) Link Surveillance and Screening Results to Other Key Providers:

- Care coordinators should ask parents about other professionals with whom the child or family is involved, such as primary care providers, child care providers, teachers, or other family support program staff who play a significant role in the child's life. Care coordinators can assist with communication between parents and providers by requesting parental consent to share any surveillance or screening results with other providers. Care coordinators can encourage parents to do the same as well. Furthermore, sharing results between providers will help to reduce repetition of screening for families among multiple providers.

For more information on Title V care coordination and billing, see the Maternal and Child Health Program Guide.

\*If care coordinators are not trained on how to administer the Ages and Stages Questionnaire developmental screening tool, go to the ASQ state trainer map in the Surveillance and Screening Tools section of this handbook to find a trainer in your area. These trainings are available for free.



## Healthy mental development in the first five years



Welcome to the 1<sup>st</sup> Five program!! 1<sup>st</sup> Five is a NO COST service program through [Agency Name]. We are here to help children and families in many ways.

- We can help families access community services such as:
  - Financial Assistance
  - Counseling
  - Help with housing and employment
  - Developmental screenings and treatment referrals for children
  - Access to community resources
  - And much more!!!

How does it work?

- Your child's doctor probably asked questions during your child's last well-child visit about stress, depression, and how your child is developing.
- If any of these issues are affecting your family and you responded that you may like some help with these issues, the doctor's office contacts 1<sup>st</sup> Five.
- A care coordinator will be calling you to get more information about the concerns you have and to help you find support and services in the community.
- This is a NO COST service and is completely voluntary. If you choose not to participate in 1<sup>st</sup> Five, just let the care coordinator know when they call that you are not interested or call 1<sup>st</sup> Five at [phone number].

What you get if you say 'yes' to 1<sup>st</sup> Five:

- A care coordinator to make phone calls and to assist you in setting up services for you and your family
- People who will help you communicate with your child's doctor and other service providers.
- And more...

We look forward to talking with you soon and serving you and your family!!

Sincerely,

[Care Coordinator Name,  
Title,  
Agency,  
and Contact Info]

## Healthy mental development in the first five years



*“Un desarrollo mental saludable en los primeros cinco años”*

¡Bienvenidos al programa Primeros Cinco (**1st Five** por su nombre en Inglés)! **1st Five** es un servicio GRATUITO a través del [Agency Name]. Aquí estamos para ayudar a los niños y familias.

- Nosotros podemos ayudar a las familias a tener acceso a los servicios comunitarios como:
  - Asistencia financiera
  - Consejería
  - Ayuda con vivienda y empleo
  - Exámenes del desarrollo de los niños
  - Acceso a los recursos comunitarios
  - ¡y mucho más!

¿Cómo trabaja todo esto?

- Quizás en la última visita su pediatra le preguntó sobre su estrés, depresión y cómo se ha desarrollado su hijo/a.
- Si algunos de estos problemas están afectando a su familia y usted ha respondido que usted quisiera ayuda con estos problemas, el doctor se comunicará con **1st Five**.
- Una coordinadora de **1st Five** le llamará para obtener más información sobre las preocupaciones que usted tenga y para ayudarlo a buscar servicios de apoyo en la comunidad.
- Este servicio es GRATUITO y es completamente voluntario. Si usted decide no participar en el programa de **1st Five**, hágale saber a la coordinadora que usted no está interesado/a o llame a **1st Five** al [phone number].

Si usted dice que “sí” al programa de **1st Five**, usted recibirá:

- Una coordinadora para hacer llamadas telefónicas y para ayudarlo a establecer servicios para usted y su familia
- Personal quien le ayudara a comunicarse con su pediatra y otros proveedores de servicios comunitarios.
- Y más...

¡Esperamos hablar con usted y servirle a usted y a su familia!

Atentamente,

[Care Coordinator Name,  
Title,  
Agency,  
And Contact Info]



# Early Childhood Iowa Collaboration

Achieving results that benefit all partners



**"Collaboration" - working together to achieve a common goal.**

Commitment

Appropriate stakeholders

Listening

Leadership

Communication

Favorable climate

Goals

Respect

Shared vision

Flexibility

Ideology

Compromise

Understanding

= Collaboration



## Builds Collaboration

- ▶ Recognize and verbalize self-interests
- ▶ Use we/our/us language when referring to the group
- ▶ Build relationships
- ▶ Take time to learn everyone's needs/roles/strengths
- ▶ Expect conflict - it can be healthy - respond appropriately
- ▶ Acknowledge/appreciate cultural/custom differences
- ▶ Develop desired short- and long-term results
- ▶ Foster a sense of shared purpose through a vision statement

## Hinders Collaboration

- ▶ Hide personal and professional motivations
- ▶ Use me/I language when referring to the group
- ▶ Exclude a wide range of partners
- ▶ Rush through important planning periods
- ▶ Ignore conflict without discussion
- ▶ Assume all personal/professional experiences are similar
- ▶ Underestimate the value of evaluation
- ▶ Submit to turf issues and losing sight of common vision and mission

**Good News** - Through collaboration all parties involved are winners! Often working with partners outside the walls of our traditional work setting seems cumbersome and even exhausting. However, learning to garner the utmost from these partners is critical in creating long-lasting positive changes for the benefit of the entire community or population. By opening the lines of communication, defining the efforts and vision of the group, and developing mutual strategies can help all organizations gain buy-in and allocate resources towards the common mission.

**Get real** - Intensity, time, efforts, and risk are needed to advance the opportunity to achieve your collaborative goals. History, Power, Competition, Teamwork, Resources and your individual actions impact collaborative efforts.

# Collaboration requires a shift in thought and action

- Competing ► Building consensus
- Working in silos (alone) ► Include others from diverse fields
- Thinking in programs, services ► Thinking systemically, larger results and strategies
- Short term accomplishments ► Long term results
- “I” ► “We” are stronger and more powerful than “I” - amplified resources (i.e. what resources does each organization bring to the table that will foster a coordinated approach to achieving your goals of positive outcomes for young children and families?)

## Four stages to building collaboration



### **Build Relationships: Individual to Individual...Start personal**

*Envision: Key factors in building the foundation of a collaborative effort*

1. Collaborations often begin as a result of a conversation or recommendation by a funding source
2. Assemble interested parties
  - a. invite people from a variety of backgrounds and fields
  - b. hold effective meetings
    - i. involve everyone in conversations at meetings
    - ii. well structured agenda
    - iii. follow-up from meetings
3. Enhance trust, by disclosing self-interests as it relates to the goals of the collaboration
  - i. risk vulnerability by being frank and honest about feelings, hesitations, past errors, and aspects of control that are difficult for each to relinquish
4. Confirm the vision of the group
  - a. through consensus of all those involved
  - b. strive to create a statement that is specific, concise, unique, and focuses on possibilities and opportunities
  - c. when future issues arise, remember that all aspects of discussion and contention (turf issues) must be looked at through the lens accomplishing the vision/mission
5. Specify desired results
  - a. short- and long-term
  - b. measurable
  - c. concrete
  - d. attainable





## Obtain Buy-in: Individual to Organizations

*Empower: Key factors in confirming the influence and reach of a collaborative effort*

*\*Remember - during these stages it is important to keep an open mind and expect the planning process to proceed slowly. Thorough planning is critical as success of results hinges on success of planning.*

1. Clarify roles of the organizations involved
  - a. when assigning roles and assessing resources, gain consent from supporting organizations
  - b. obtain letters of commitment that detail the mission, objectives, and strategies of the collaboration
2. Manage and resolve the conflict
  - a. expect and embrace some conflict
  - b. state name fears, as they are often fueled by misconceptions and source of turf issue - through discussion, separate feelings and actual consequences of potential change
  - c. define issues at hand
  - d. celebrate the resolution of conflict
3. Remain flexible as needs, resources, and priorities of the collaboration evolve
4. Organize the efforts of the group - create a diagram of components of the collaboration
  - a. determine roles of members and support them through their works
    - i. develop communication plans
    - ii. decide on "decision-makers" and the protocol of decision making



## Proceed with Action Plan: Organization to Organization

*Ensure: Key factors in solidifying the success of a collaborative effort*

*This is where the rubber hits the road and the collaboration begins to see outputs and the benefits of the planning process are reaped.*

1. Revisit the vision and determine if it is still guiding the planning and work of the group and evaluate its current appropriateness for the group
  - a. include direct service workers and consumers of the target population in this process
  - b. assess local resources and data as well as current needs assessment
2. Outline and proceed with the action plan
  - a. take advantage of existing structures and initiatives
  - b. accountability is important in achieving high quality results - includes standards
3. Encourage collaborative work habits
4. Organize the efforts of the group - create diagram of components of the collaboration
  - a. share successes
  - b. think all the way through the impacts of decision - community, organization, and individuals involved
    - i. barriers, united consequences, gains, etc.
    - ii. articulate who might be opposed to your mission (turf issues) and consider inviting them to join to reduce resentment and misunderstanding - defuse mistrust through open dialogue of group mission/vision and strategies
  - c. enact communication plan and share information broadly
  - d. allow and accept change and learn to forgive
  - e. celebrate achievements

5. Evaluation is necessary and beneficial
  - a. evaluate results and processes - be honest about successes and failures
  - b. there may be qualitative and quantitative data that are useful
  - c. utilize results to improve collaboration and maintain report
  - d. renew commitment and focus of group - review membership, results, and evolution of collaboration
  - e. understand that current and future needs may be different than initial needs of the group
6. Celebrate!
  - a. recognize members and organizations for their achievements



## **Spread the Word: Organization to Community**

*Endow Continuity: Key factors in solidifying sustainability of a collaborative effort*

*"Creating visibility was our way of obtaining greater resources for a great impact for our effort." (123)*

1. Generate visibility
  - a. image of collaboration should be seen as leader
  - b. succinct message to convey mission of collaboration
2. Promote results through targeted messaging
  - a. create a strategic plan for communication with the public and expanding to diverse interest groups
3. Involve the community
  - a. this will create momentum and encourage sustainability
  - b. educate the community on what benefits "we" are reaping through "our" working together
4. Systems change
  - a. through public input and appropriate stakeholders, systems can be influenced towards the mission of the collaboration
  - b. plan changes based on need and identify possible points of persuasion in the system
4. Understand that some collaborations need to come to an end
  - a. people and relationships may change
  - b. community needs have shifted and results have been achieved

# *Teamwork!*

Successful collaborations speak on behalf of the power of teamwork and putting the needs of the community above separate interests. Collaborations provide opportunities to include diverse groups, identify service gaps and network organizations for the greater good of the community. Some of the many advantages of interdisciplinary/cross-system collaboration are: assembles diverse expertise, promotes focus on common goals, cultivates sustainability, appeals to funders, and expands the base for advocacy (Kagan, 2006). Building trusting relationships, thorough planning, commitment, and strong leadership are especially key in developing successful collaborative efforts in a more focused way.

# Retaining Collaboration Members

Remember that all partners are not the same, as people speak different languages, adhere to different administrative codes/ rules, have different values. However, having a diverse membership is critical in enhancing the work of the collaboration. Help people feel included and they feel they are making a contribution to the group. People will remain engaged and motivated if they are comfortable with the group's personality and leadership and personal and group goals are being met. As to new members, create ways to integrate them into the already existing connections.



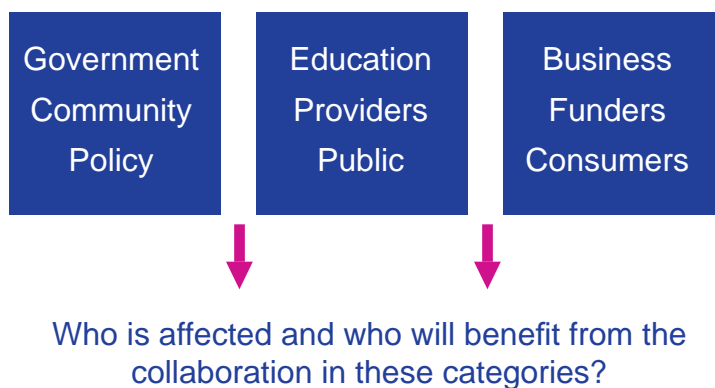
## Suggestions:

“mentor” systems ► new member packets ► accessible meetings ► sense of team spirit ► incentives

Elements	Cooperation
<b>Risk</b>	Low intensity
<b>Vision</b>	<ul style="list-style-type: none"> <li>▪No common vision/mission, common goals</li> <li>▪Shorter term or indefinite</li> </ul>
<b>Relationships</b>	<ul style="list-style-type: none"> <li>▪Interaction as needed</li> <li>▪Informal relations</li> </ul>
<b>Structure</b>	<ul style="list-style-type: none"> <li>▪Each organization remains autonomous, individual accountability</li> </ul>
<b>Responsibility</b>	<ul style="list-style-type: none"> <li>▪Little collective planning</li> </ul>
<b>Communication</b>	<ul style="list-style-type: none"> <li>▪Information shared as necessary</li> </ul>
<b>Leadership</b>	<ul style="list-style-type: none"> <li>▪Little shared leadership</li> </ul>
<b>Resources</b>	<ul style="list-style-type: none"> <li>▪Remain within “own” organization</li> </ul>
<b>Results</b>	<ul style="list-style-type: none"> <li>▪Serve individual organizations needs</li> </ul>

# Activity for Building a Collaboration

In an initial meeting, using large poster paper, list all partners that might benefit the collaboration using the categories shown below. Be creative and unafraid to ask people to be involved. Asking people allows them the opportunity to do so. Often groups or people want to be involved, but do not know how to initiate a large movement.



# Tips for Collaboration Members

## Think about...

- ▶ Who is at the table?
- ▶ Who needs to be at the table?
- ▶ Identify potential workgroups
- ▶ Think outside the box

## 6 R's of Participation

Recognition  
Respect  
Role  
Relationship  
Reward  
Results

*Kayne and Wolff, 1995*

Coordination	Collaboration
→ → →	High intensity
<ul style="list-style-type: none"> <li>▪ Missions and goals of organizations are compatible</li> <li>▪ Specific effort or program</li> </ul>	<ul style="list-style-type: none"> <li>▪ New, common mission and goals are established</li> <li>▪ Long term results</li> </ul>
<ul style="list-style-type: none"> <li>▪ Interaction around project or task</li> <li>▪ More formal relations</li> </ul>	<ul style="list-style-type: none"> <li>▪ Variable number of projects</li> <li>▪ Formal with full support of "own" organizations</li> </ul>
<ul style="list-style-type: none"> <li>▪ Organizations contribution of time increases, while remaining independent and mostly individually accountable</li> </ul>	<ul style="list-style-type: none"> <li>▪ Each represented organization fully commits to common mission, and has shared accountability</li> </ul>
<ul style="list-style-type: none"> <li>▪ More specific planning and division of roles</li> </ul>	<ul style="list-style-type: none"> <li>▪ Each represented organization fully commits to common mission, and has shared accountability</li> </ul>
<ul style="list-style-type: none"> <li>▪ Purposeful and defined channels</li> </ul>	<ul style="list-style-type: none"> <li>▪ Multi-levels of definite routes of communication, open, clear and (frequent)</li> </ul>
<ul style="list-style-type: none"> <li>▪ Some collective leadership</li> </ul>	<ul style="list-style-type: none"> <li>▪ Shared and multiple levels of leadership</li> </ul>
<ul style="list-style-type: none"> <li>▪ Are recognized and available</li> </ul>	<ul style="list-style-type: none"> <li>▪ Are shared and managed by the collaboration</li> </ul>
<ul style="list-style-type: none"> <li>▪ Acknowledged and shared</li> </ul>	<ul style="list-style-type: none"> <li>▪ Shared in products, mutually beneficial</li> </ul>

## **This document was developed based on the following works:**

Winer, Michael & Ray, Karen. Collaboration Handbook: Creating, Sustaining, and Enjoying the Journey. Amherst H. Wilder Foundation. St. Paul, MN. 1994.

### **Presentations:**

Butterfoss, Frances D., "Building and Sustaining Successful Oral Health Coalitions,"  
April 1, 2008. 2008 Iowa Public Health Conference

Johnson, Kay, "Partnerships to Improve Child Health," April 28, 2006. Des Moines, Iowa.





# Health Coalition Framework

**Member  
Organization**

**Government**  
Health Dept  
Environmental  
Health  
Dept of Ed  
Dept of Social  
Services  
Mayor's  
Office  
City Council  
Housing  
Authority

**Community**  
Community-  
based  
Clinics  
Civic Leagues  
Faith-based  
Orgs  
Foundations  
Youth Groups  
CBOs

**Education**  
School  
Administrators  
PTA  
Professional  
Assoc.  
County  
Extension  
Universities &  
Colleges  
Professional  
Schools

**Providers**  
Dentists  
RNs  
Nurse  
Practitioners  
Pas  
Physicians  
Pharmacists  
Hospitals  
Professional  
Associations

**Public**  
Consumer &  
Patient Care  
Parent Orgs  
Senior Citizen  
Orgs  
Advocates  
Quality  
Improvement  
Orgs  
Civil Rights  
Orgs  
Support  
Groups

**Funders &  
Third-Party  
Payers**  
Managed care  
Insurance  
Medicaid  
Medicare  
Foundations

**Policy**  
State/Federal  
Legislators  
Lobbyists  
Advocates  
Policy Makers

**Business**  
Local  
businesses  
Fortune 500  
Cos.  
Chamber of  
Commerce  
Business  
Council  
Unions  
Banks  
Media Orgs

## Potential Working Groups

Assessment & Evaluation

Specific Populations (e.g., age, gender, race, ethnicity)

Prevention & Treatment Programs

Policy

Funding

Communications/Marketing

Data & Surveillance

Specific disease of issue areas (e.g., cancer, oral health)

Access to Care

Quality of Care

Education

Considered an Active  
Coalition if these outputs  
are identified

- Written vision/mission statements
- Written Priorities/plans/strategies
- Identified stakeholders
- Responsibilities for implementation

- Legislative Activity
- Communication products
- Products & Impact
- Sustainability (funding & institutionalization)

## **Groups to Contact to Build More Diverse Coalitions**

### **Labor/Employment**

- ☐ Workers and their unions (e.g., hotel workers, automobile workers, etc.)
- ☐ AFL-CIO and its chapters
- ☐ AFSCME and its chapters
- ☐ SEIU and its chapters
- ☐ Businesses (esp. local/community businesses)

### **Religious/Faith-Based**

- ☐ Local places of worship (e.g., churches, synagogues, mosques) and groups based in places of worship
- ☐ National religious organizations
- ☐ Other faith-based organizations (e.g., religious student groups, etc.)

### **Local Community**

- ☐ Community action and consumer advocacy groups
- ☐ Community health centers and their staff
- ☐ Clients of community health centers
- ☐ Local housing and homeless coalitions
- ☐ Recognized community/neighborhood leaders

### **Family/Children/Elderly**

- ☐ Organizations focusing on children and families
- ☐ National/Local chapters of March of Dimes
- ☐ Parents of children with special needs
- ☐ Senior advocacy groups
- ☐ National/Local chapters of NAACP
- ☐ Others: United Seniors

### **Ethnic**

- ☐ Organizations protecting health needs/rights of people of color
- ☐ National/Local chapters of NAACP
- ☐ National Council of Negro Women
- ☐ National Council of La Raza
- ☐ North American Indian Legal Services, National Congress of American Indians

### **Women**

- ☐ Organizations protecting the health needs/rights of women
- ☐ National Organization for Women
- ☐ League of Women Voters
- ☐ National Women's Health Network/National Women's Health Organization
- ☐ Others: YWCA, Big Sister Association, MADD

**Health Advocacy/Medical Issues**

- ☐ University-based health law and health care justice advocates
- ☐ Representatives and employees of local health clinic/hospitals
- ☐ Disability rights organizations (e.g., National Alliance for the Mentally Ill)
- ☐ Medicaid and Medicare beneficiaries and their advocates
- ☐ Others: American Cancer Society, American Lung Association

**Professional/Trade Associations**

- ☐ Primary Care Associations
- ☐ Hospital Associations (e.g., National Association of Children's Hospitals)
- ☐ Medical Societies, American College of Physicians
- ☐ Nurses/Nurse-Midwives/Physician Assistants Associations
- ☐ Small business associations

**Multiple Interest Groups**

- ☐ Lesbian and Gay Law Association, Gay and Lesbian Medical Association
- ☐ National Latina Health Organization
- ☐ National Hispanic Employee Association
- ☐ National Black Women's Health Project
- ☐ National Asian Women's Health Organization
- ☐ Catholic Health Association, Catholic Charities, National Council of Jewish Women

**Other Possibilities**

- ☐ Student groups (e.g., fraternities, sororities, alumni associations, SADD)
- ☐ Immigrant interests: migrant worker rights groups
- ☐ Regional: National Rural Health Association
- ☐ Local affiliates of national organizations (e.g., AARP, NAACP, YMCA)
- ☐ Political groups

From Community Catalyst. (2003). A Guide to Building Community Coalitions. P. 19-20

## **Model Commitment Letter: Coalition Organizations**

Our Organization, [NAME], is committed to be an active member of the [NAME] Coalition. We are committed to the vision, goals, objectives and strategies that have been and/or will be decided by the Coalition. We are committed to the planning and collaboration that such coalitions undertake and understand that it will take time. We acknowledge the contributions and expectations of the other member of the Coalition. Benefits of membership include: newsletters, access to coalition Web site and its resources, education events, connection to other members and priority populations, - \_\_\_\_\_ [SPECIFY ANY OTHERS THAT APPLY].

### **As general evidence of our commitment, we agree to do the following:**

- ☐ Appoint a representative(s) to attend coalition meetings and activities;
- ☐ Authorize that representative to make decisions on our behalf, except for decisions regarding \_\_\_\_\_ [SPECIFY EXCEPTIONS, IF APPROPRIATE];
- ☐ Read minutes, reports and newsletters to keep abreast of coalition decisions and activities;
- ☐ Disseminate relevant information to organizational members or employees through list serves, Web sites and newsletters;
- ☐ Keep coalition informed of our organization's related activities.

### **Specifically, our organization will commit the following resources to the coalition:**

- ☐ Access to our volunteers for coalition tasks;
- ☐ A financial commitment for \$\_\_\_\_\_ [OR DUES, IF APPROPRIATE];
- ☐ In-kind contributions of staff time, material resources, meeting space, refreshments, incentive items \_\_\_\_\_ [SPECIFY];
- ☐ Connections to other key organizations or individuals \_\_\_\_\_ (SPECIFY).

## Potential Member Grid

<b>Organization or Individual</b>	
Activities & accomplishments	
Contributions (power, time, talent, resources)	
Self-interest (personal & organizational gains)	
Potential conflicts	
<b>Organization or Individual</b>	
Activities & accomplishments	
Contributions (power, time, talent, resources)	
Self-interest (personal & organizational gains)	
Potential conflicts	
<b>Organization or Individual</b>	
Activities & accomplishments	
Contributions (power, time, talent, resources)	
Self-interest (personal & organizational gains)	
Potential conflicts	
<b>Organization or Individual</b>	
Activities & accomplishments	
Contributions (power, time, talent, resources)	
Self-interest (personal & organizational gains)	
Potential conflicts	

## 6 R's of Participation: Involving and Mobilizing Coalition Members

By understanding why community members participate in a coalition, you take the first step toward developing strategies to ensure their inclusion. Prospective members expect to have certain roles and power. Why would someone want to be involved in your coalition? How does it benefit him or her? Your coalition will be successful when it meets members' needs.

1. **Recognition.** People want to be recognized for their leadership. We all want to be known, initially by the members of our own group and then by others, for our contributions to a better quality of life.  
*Tip:* You can recognize contributions through awards and dinners, and by highlighting and praising members at public events.
2. **Respect.** Everyone wants respect. By joining community activities we seek the respect of our peers. People often find that their values, culture, or traditions are not respected in the workplace or community, so they seek recognition and respect for themselves and their values by joining community organizations and coalitions.  
*Tips:* Don't schedule all of your planning meetings during regular working hours, but meet in the evenings and provide dinner and childcare. Translate materials into languages for non-English speaking members and provide translators.
3. **Role.** We all like to feel needed; we want to belong to a group in which our unique contribution is appreciated. Groups must find a role for everyone if they expect to maintain a membership.  
*Tip:* Grassroots leaders and members may have experienced being "tokens" on coalitions. Create roles with power and substance.
4. **Relationship.** Organizations are networks of relationships; often a personal invitation convinces someone to join. People may sign up for private reasons (say, to make new friends) and for public reasons as well (to broaden a base of support or influence, for example). People may also join to get connected to "power player" in your coalition. Organizations draw us into a wider context of community relationships that encourage accountability, mutual support, and responsibility.  
*Tip:* Provide real opportunities for networking with other institutions and leaders.
5. **Reward.** Organizations and coalitions keep members and attract new ones when the rewards of membership outweigh the costs. Not everyone is looking for the same kinds of rewards. To sustain members' role in your coalition, try to identify their interests and find out what public and private rewards suit them.  
*Tip:* Schedule social time and interaction into the agenda of the coalition so families can participate. Make sure there is an ongoing way to share resources and information, including funding opportunities and access to people in power.
6. **Results.** Nothing works like results! An organization that cannot deliver the goods will not continue to attract people and resources. If your coalition is formed in response to negative forces in the community (e.g., rising crime rates), safer streets will obviously be welcome and enhance your coalition's credibility. Build visible, short-term successes to your work.  
*Tip:* To many grassroots leaders and residents, visible projects and activities that directly affect conditions and issues in their communities are the results they want in return for their participation.



## Six R's of Participation- Worksheet

<b>1. Recognition</b>	
What do we know now?	What could we do?
<b>2. Respect</b>	
What do we know now?	What could we do?
<b>3. Role</b>	
What do we know now?	What could we do?
<b>4. Relationship</b>	
What do we know now?	What could we do?
<b>5. Reward</b>	
What do we know now?	What could we do?
<b>6. Results</b>	
What do we know now?	What could we do?



<b>1<sup>st</sup> Five Coalition Meeting Agenda</b> <b>[TIME]</b> <b>[LOCATION]</b>			
<b>Time</b>	<b>Topic</b>	<b>Discussion Points</b>	<b>Meeting Notes</b>
	<b>Welcome</b>  <i>All</i>	Introductions	
	<b>1<sup>st</sup> Five Overview</b>  <i>Site Coordinator</i>	Background <ul style="list-style-type: none"> <li>• Brief History of 1<sup>st</sup> Five/ABCD II</li> <li>• Local Application of 1<sup>st</sup> Five Model (How it works in your area)</li> <li>• Current Local Activities/Results Year-To-Date</li> </ul>	
	<b>Potential Work Groups (or can use list to prioritize future meeting agendas)</b>  <i>Site Coordinator &amp; All</i>	Potential Working Groups <ul style="list-style-type: none"> <li>• Funding/Relationship Building for Public-Private Partnerships</li> <li>• Assessment &amp; Evaluation</li> <li>• Policy</li> <li>• Communications/Marketing</li> <li>• Access to Care</li> <li>• Specific Outreach to Populations (e.g., age, gender, race, ethnicity)</li> <li>• Data &amp; Surveillance</li> <li>• Quality of Care</li> </ul>	

		<ul style="list-style-type: none"> <li>• Work Force Training</li> <li>• Local Systems Building for Early Childhood</li> </ul>	
	<b>Program Barriers</b> <i>Site Coordinator &amp; All</i>	Areas for Improvement <ul style="list-style-type: none"> <li>• Highlight main barriers to program implementation</li> <li>• Input/expertise from coalition members</li> </ul>	
	<b>Wrap-up &amp; Future Decisions for next meeting</b> <i>All</i>	<ul style="list-style-type: none"> <li>▪ Future meeting topics?</li> <li>▪ Are we missing critical partners for our coalition?</li> <li>▪ How do we elicit feedback and make decisions?</li> <li>▪ How can we build an effective coalition?</li> </ul>	



## TIP SHEET

These tips are intended to help ensure **SUSTAINABILITY** for your community-based program. Even if you only implement a few, you will make a difference!



These tips were gathered by Healthy Tomorrows staff. Visit [www.aap.org/compeds/httpcp](http://www.aap.org/compeds/httpcp), e-mail [healthyt@aap.org](mailto:healthyt@aap.org), or call 847/434-4279 for more information.

## SUSTAINABILITY

- Start thinking and working on sustainability at the beginning of your project.
- Utilize and maximize existing program resources.
- Start small and build on successes.
- Track data and collect individual stories to strengthen program support.
- Advocate to create community awareness about your program.
- Involve your advisory board to connect you to your community.
- Network with those who may benefit from what you do and vice versa.
- Ask yourself the following question: How can we make the program better?
- Build strong relationships with key stakeholders.
- Involve families and community members at every step.
- Look for resources and funding opportunities continuously.
- Implement your evaluation plan by developing a logic model with measurable outcomes.
- Thank your funders and supporters regularly.
- You are on your way to helping change your community!

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## Sustainability Tools – 10 Steps to Maintaining Your Community Improvements

The Sustainability Toolkit: 10 Steps to Maintaining Your Community Improvements grew out of the Center for Civic Partnerships' efforts to provide technical support to collaboratives and organizations on sustaining their community improvements. As we tested different processes with groups, we developed a 10-step process to guide communities through sustainability planning. Below is a brief description of the 10 steps. We have provided links to additional reading at the end. If you would like descriptions of the activities and additional tools for sustainability based on these steps, you can download the toolkit order form at Sustainability Toolkit or call 916-646-8680 to have an order form sent to you.

We provide a variety of training and consultation services to help groups develop, implement and sustain community improvements. We would welcome an opportunity to discuss how the sustainability process and materials might be of benefit to your organization or coalition. Please contact Val Sheehan, Program Manager, at 916-646-8680 or [vsheehan@civicpartnerships.org](mailto:vsheehan@civicpartnerships.org) for additional information, current references and/or rates.

### 10 Steps to Sustainability

- 1. Create a shared understanding of sustainability.**

Sustainability means different things to different people. To some, it's about getting more money. To others, it's about keeping partners and volunteers engaged. It may even get someone thinking about new things for the group to do. These different definitions of sustainability point out the need for a group working on sustainability to come up with a common definition.

While there are a number of sustainability definitions in the literature, we have chosen a broad definition, which can include improvements in education, employment, housing and other areas, along with more traditional healthcare and public health improvements.

- 2. Sustainability: The continuation of community health or quality of life benefits over time.**

Position your effort to increase your sustainability odds.

There are a number of factors that influence the likelihood that you will be able to sustain your community improvements. These include a number of choices made at the beginning of an effort and throughout implementation. In the planning stages of an activity, it is wise to consider creative ways to ensure that the loss of one source of funding won't severely jeopardize continuation. One group that created a neighborhood resource center asked each participating organization to provide services in the resource center using their existing funds (vs. having one grant pay for all of the services). This way, even if one agency could no longer provide a service, the majority of the activities would remain.

- 3. Create a plan to work through the process.**

With any strategic planning process, it helps to think through the details of the process before you begin. Who needs to be involved (e.g., coordinator, subcommittee, facilitator)? How long will it take? What is the commitment of the individuals involved?

**4. Look at the current picture and pending items.**

Before you begin to decide which activities to continue, it is important to have a clear picture of what you are currently doing. With busy people and organizations that are involved in a variety of programs, it's easy to overlook something. A simple way to make sure that the group is clear on the activities under discussion is simply to present a list of the efforts. It can also help at this stage to look at upcoming events (e.g., pending funding, policy changes, new projects) that may impact continuation of one or more of your efforts.

**5. Develop criteria to help determine what to continue.**

Engaging in a criteria exercise can assist the group in looking more critically at whether or not activities should be continued. We recommend that the group select the 3-5 most important questions (or criteria) that they want answered before they can decide what to continue. Potential criteria include questions of impact, capacity to continue, broad community support and continued need. Gather/review the information needed and answer these questions about each of your activities listed in the prior step.

**6. Decide what to continue and prioritize.**

Now it's time to decide which efforts your group should continue (or ask others to take over). Many groups have difficulty making these types of decisions. They don't want to admit that something hasn't worked, especially if a member is passionate about the activity. Perhaps discontinuing an effort will lead to staff having to find other jobs. It can be extremely helpful to have a skilled, neutral facilitator for this step.

Most likely, there will be some activities that will not be continued. Some efforts may simply be complete and don't need to be repeated in the near future (e.g., policy forum or health fair). Other programs may not have been successful. While you will not be continuing these efforts after the current funding ends, it is important not to forget about them. In any case, make sure you complete the necessary steps to close out these activities. Also, if it is a client-based service (e.g., injury prevention program), help the individuals transition into another program and/or give them suggestions on where to go for assistance.

**7. Create options for maintaining your priority efforts (including funding issues).**

Now that you have decided what you want to continue, it's time to figure out how to make it happen. Fortunately, there is a lot of information out there to assist you, especially when it comes to fundraising. Flexibility is a key concept for this phase of your planning. It is important to be flexible in exploring potential options for continuation. Just because you decide to continue an existing effort doesn't mean that the same organization may be doing it in the same way.

**Some of the things to consider in this stage are:**

What results have you achieved that justify continuing this effort?

To whom is this effort important (or who benefits) and do you have their commitment to finding resources (not necessarily money) for this effort?

What cost effectiveness, cost savings or other financial justification can you document for this effort?

What resources (financial and other) are needed to continue?

What are some possible sources of resources for continuing this effort?

**8. Develop a sustainability plan.**

Developing a concrete plan and creating a short summary of it will help your group organize the information and stay on track.

**We recommend that you develop two documents as part of your sustainability plan:**

An action plan, which lists the steps to be accomplished, the due dates and who will be responsible for implementing each step. Verify that your timeline is realistic and won't leave a gap between when the current funding ends and when the new resources would begin.

A brief summary, to be used as a marketing document. On one sheet of paper (double-sided), briefly explain who your group is, highlight a few key accomplishments/outcomes, describe what you want to continue and list what you need for that to happen (policy change, in-kind support, another organization to take over a project, financial resources, etc.). Make many copies of this document and share it with everyone (e.g., colleagues, funders, neighbors, friends and association members). You never know who will help you find the resource you need.

**9. Implement your sustainability plan.**

You've made it through the planning and now you're ready for implementation. Grab that action plan and get to work! Check in with the individuals involved in carrying out the plan activities to see how things are going. Remain open to new opportunities that may arise, which are better than your original option. Marketing and networking are very important in this phase. It may help to secure additional assistance (staff, consultants, interns and/or volunteers) to help balance the regular project tasks with the sustainability activities. Keep people engaged and celebrate as you find resources for continuation.

**10. Evaluate your outcomes and revise as needed.**

Review the list of efforts you wanted to continue – have you secured the necessary resources (e.g., funding, in-kind commitments)? As you implemented your plan, you may have had to pursue more than one option or change your strategy. If you are not able to continue an activity, you may have to revise your plan and phase down the effort instead. It helps to think back to the beginning of this process for a moment. The goal of sustainability is the continuation of community health and/or quality of life benefits over time. Make sure there is a mechanism in place to monitor whether the efforts continue to improve the health of your community.

## **Suggested Reading**

Center for Civic Partnerships, Public Health Institute (2001). Sustainability Toolkit: 10 Steps to Maintaining Your Community Improvements. Oakland, CA: Public Health Institute. Get the order form at Sustainability Toolkit or call 916-646-8680.

Community Toolbox Website Community Toolbox - contains a variety of collaborative tools for building healthy communities. Refer to Chapters 42 (Getting Grants and Financial Resources) and 46 (Planning for Long-Term Institutionalization).



David, T. (2002). Reflections on Sustainability. Woodland Hills, CA: The California Wellness Foundation. Available: [www.tcdf.org/reflections/2002/feb/](http://www.tcdf.org/reflections/2002/feb/).

The Finance Project (2002). Sustaining Comprehensive Community Initiatives: Key elements for success. Washington, DC: The Finance Project. Available: [www.financeprojectinfo.org/Publications/sustaining.pdf](http://www.financeprojectinfo.org/Publications/sustaining.pdf).

Shediac-Rizkallah, M. C. and Bone, L. R. (1998). Planning for Sustainability of Community-based Health Programs: Conceptual Frameworks and Future Directions for Research, Practice and Policy. Health Education Research, 13(1), 87-108. Available: [www3.oup.co.uk/healed/hdb/Volume\\_13/Issue\\_01/pdf/130087.pdf](http://www3.oup.co.uk/healed/hdb/Volume_13/Issue_01/pdf/130087.pdf) or send reprint request to Lee R. Bone, Department of Health Policy and Management, School of Hygiene and Public Health, The Johns Hopkins University, 624 North Broadway, Baltimore, MD, 21205.

Wolff, T. (1994, May/June). Sustainability of Coalitions (Coalition Building Tips). AHEC/Community Partners. Available on the Web at: [www.compartners.org/community/resources/cb\\_sustainability.pdf](http://www.compartners.org/community/resources/cb_sustainability.pdf).

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## Healthy mental development in the first five years



(SITE COORDINATOR NAME)

**1st Five** Healthy Mental Development Initiative

(TITLE V AGENCY NAME)

(ADDRESS)

(PHONE NUMBER)

(DATE)

Dear (COMMUNITY PARTNER NAME) Staff:

Because of the vital service that (COMMUNITY PARTNER NAME) provides in working to improve the health and well-being of children and families in (NAME OF COUNTY), I am writing to let you know about an exciting new child and family health initiative in our community.

**Who we are:** My name is (NAME), and I am the site coordinator for the **1st Five** Healthy Mental Development Initiative for (NAMES OF COUNTIES). Iowa's **1st Five** Healthy Mental Development Initiative is an Iowa Department of Public Health program that works to build partnerships between physician practices and public service providers to improve high-quality well-child care. **1st Five** promotes the use of standardized developmental surveillance and screening tools that support healthy mental development for young children during the first five years. Since 2006 the **1st Five** initiative has been expanding across Iowa; currently, (NAME OF COUNTY) is one of fourteen counties involved in the **1st Five** initiative. As a part of this enhanced service delivery model, we at (NAME OF TITLE V AGENCY) link families to community resources such as your agency as part of our referral and follow-up services to medical practices.

The enclosed materials further outline how this public-private partnership and program model work.

I will be contacting you within (# OF DAYS OR WEEKS) to learn more about your (COMMUNITY PARTNER NAME) programs as part of our referral network for families, as well as answer any questions you may have about **1st Five**. I look forward to talking with you.

Sincerely,

(NAME)

**1st Five** Site Coordinator

## Community Linkages [A Community Planning Activity]

## 1<sup>st</sup> Five Project: County

Community Linkages *	Current Linkages					Linkage Assessment			1 <sup>st</sup> Five Planning Linkage Activities
	No linkage	Communication	Cooperation	Coordination	Collaboration	Strengths/Linkage in Place	Barriers & Gaps	Capacity for Receiving Increased Referrals	
Area Education Agencies									
Child Care Resource And Referral or HCCI									
Child Health Specialty Clinics									
Community Health Centers									
Early ACCESS Services									
Early Childhood Iowa Areas									
Head Start/Early Head Start									
Healthy Start HOPES Project/Other Home Visitation Programs									
Hospitals									
Immunization Providers									
Lead Screening Programs									
Local Department of Human Services									
Local physicians for referral									
Maternal Health Programs									
Mental Health Programs									

Services to the Homeless/Migrant Workers Services for Minority/Vulnerable/Undocumented Population Migrant Health Centers									
WIC Programs									
Other (specify):									

\* Include a one-page narrative for unique linkages in their service delivery areas.

# Community Linkages Continuum Model

## Model

The linkages are determined on a variety of factors, such as the availability of services and programs within the service delivery area and the demographics of the audience(s) served by the child health center. A child health center will be at different levels on the continuum with different community partners. As linkages progress along the continuum, the intensity of the linkage increases (i.e., risk, time, opportunity, commitment, etc.).

	Community Linkage Continuum			
	<i>Communication</i>	<i>Cooperation</i>	<i>Coordination</i>	<i>Collaboration</i>
<b>Purpose, Vision, and Relationships</b>	<ul style="list-style-type: none"> <li>• Dialogue</li> <li>• Understanding</li> <li>• Clearinghouse for information</li> <li>• Between individuals and interaction is on an as needed basis</li> </ul>	<ul style="list-style-type: none"> <li>• Limit duplication</li> <li>• Create base of support</li> <li>• Between individuals and interaction is on an as needed basis</li> </ul>	<ul style="list-style-type: none"> <li>• Share ideas and resources</li> <li>• Fill gaps</li> <li>• Review missions and goals for compatibility</li> <li>• Relationships are supported by the organizations they represent</li> <li>• Interaction is usually around one specific project or task of definable length</li> </ul>	<ul style="list-style-type: none"> <li>• Combine resources</li> <li>• Create and implement shared mission and vision</li> <li>• Commitment of the organizations and their leaders is fully supported by their representatives</li> <li>• One or more projects are undertaken for longer term results</li> </ul>
<b>Structure, Responsibilities, and Communication</b>	<ul style="list-style-type: none"> <li>• Relationships among individuals</li> <li>• Informal "round table" as needed</li> </ul>	<ul style="list-style-type: none"> <li>• Semi-formal links</li> <li>• Project-specific roles somewhat defined</li> <li>• Each organization functions separately</li> <li>• Information is conveyed as needed</li> </ul>	<ul style="list-style-type: none"> <li>• Long-term commitment</li> <li>• Organizations involved take on needed roles but function relatively independently of each other</li> <li>• Joint planning</li> <li>• Definite channels for regular communications established</li> </ul>	<ul style="list-style-type: none"> <li>• New organizational structure and clearly defined, interrelated, and formalized roles</li> <li>• Comprehensive planning is required that includes developing joint strategies and measuring success in terms of impact on the needs of those served</li> <li>• Several levels of communication are established</li> <li>• Fully committed organizations</li> </ul>

*Continued on next page*

## Community Linkages Continuum Model, Continued

	Community Linkage Continuum ( <i>continued</i> )			
	<i>Communication</i>	<i>Cooperation</i>	<i>Coordination</i>	<i>Collaboration</i>
<b>Leadership and Accountability</b>	<ul style="list-style-type: none"> <li>• Self-initiated</li> <li>• No joint decisions</li> <li>• Little conflict</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitative leaders</li> <li>• Some specific decisions made</li> <li>• Semi-formal communications within central group</li> <li>• Leadership is unilateral and control is central</li> <li>• All leadership and accountability rests with the individual organizations which act independently</li> </ul>	<ul style="list-style-type: none"> <li>• Shared leadership</li> <li>• Group decision making</li> <li>• Some sharing of leadership and control</li> <li>• Some shared risk</li> <li>• Authority rests with the individual organizations but there is coordination among participants</li> </ul>	<ul style="list-style-type: none"> <li>• Consensus-based decision making</li> <li>• High levels of trust and leadership</li> <li>• Leadership is disbursed and control is shared mutually</li> <li>• Equal risk is shared by all organizations</li> <li>• Authority is determined by the collaboration to balance ownership by the individual organizations with expediency to accomplish a purpose</li> </ul>
<b>Resources and Rewards</b>	<ul style="list-style-type: none"> <li>• Resources are separate</li> </ul>	<ul style="list-style-type: none"> <li>• Resources (staff time, dollars, capabilities) are separate, serving the individual organizations needs</li> <li>• Resources may be known to others</li> </ul>	<ul style="list-style-type: none"> <li>• Resources may be available for specific project</li> <li>• Rewards are mutually acknowledged</li> </ul>	<ul style="list-style-type: none"> <li>• Resources are pooled or jointly secured for a long-term effort that is managed by the collaborative structure</li> <li>• Organizations share in the products, more is accomplished jointly than could have been individually</li> <li>• Synergy</li> </ul>

### Reference

Mattessich, P. & Monsey, B. (1992). *Collaboration: What Makes it Work*. St. Paul, MN: Amherst H. Wilder Foundation.

## **Getting Started With Knowing Your Community**

### **Assess care coordination and referral processes for young children in your community:**

- Who links physician offices with community-based services?
- Is there a community resource directory already available? What entity maintains this list?
- Who can provide input on community resources? Service providers? Agency clients?
- Do physician practices receive follow-up information from social service/community-based referrals?
- Do parents receive depression or stress screening at well-child exams?
- Do pediatric providers know where to refer parents for adult depression?

### **Identify your local coalition:**

- How can you elicit support from leadership in your organization and in your community?
- Who are your stakeholders?
  - Physician groups/associations/chapters
  - Nurse associations/physician assistants
  - Payers – Medicaid and private insurers
  - Community-based service providers and their funders
  - Title V/ Public Health
  - Part C/Early Intervention services
  - Legislators/the Governor's office
  - Child advocacy/public policy groups
  - Parents/Family advocates
  - Local AEAs
- Where are your stakeholders on this issue? Do they need more education or are they supportive and ready to act?
- Who will convene the stakeholders and lead this effort?
- Who is the champion for the issue? Who can affect policy change?
- Who will lead practice change? Who will be your biggest promoter?
- Who or what will be your biggest barrier?

### **Lunch-n-Learn/Coalition meetings:**

- Examples of previous topics from 1<sup>st</sup> Five Sites:
  - Refugee and Immigrant Needs
  - Toxic Environments for Children
  - Fatherhood and Supporting Young Children's Development
  - Oral Health Services
  - ASQ-3 trainings
  - Contemporary Iowa Child Health Care
  - Screening for Early Autism Detection



- Screening for Maternal Depression, Family Stress and other risk factors
- Family 2 Families Program Support Services for families with children with special health care needs
  
- How to discuss sensitive topics with parents
- How to deliver difficult news to parents
- How to discuss culturally sensitive issues
- Who comes:
  - Mental health providers, primary care providers, AEA's, school districts, non-profits with similar interest in supporting families, those who they refer to, similar interests in advocacy, 0-3 provider population, family support programs, community health centers, child advocacy support programs
- Lessons learned:
  - Give adequate advance notice, require RSVPs, keep and update mailing list, send out reminder, provide food, ask for dietary needs, vary menu, follow up with attendees